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**INVESTIGATING THE EXPERIENCES  
OF PEOPLE WITH 'RSI': AN INTERNET  
BASED QUALITATIVE STUDY**

**MOHINDER WATSON**

**A thesis submitted in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy**

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2009**

## **Abstract**

This internet-based qualitative study aimed to explore the subjective experience of having Repetitive Strain Injury (RSI) from an 'insider's perspective'.

A purposive sample of RSI sufferers was recruited from an online support group covering diverse experiences of men and women across different age groups, occupations, health care use and with both clinically recognised RSI conditions and diffuse non-specific RSI. Data triangulation involving the documentary analysis of 468 archived e-mail postings and 5 asynchronous online focus groups (n=57) was used to illuminate different aspects of RSI sufferers' experiences. Data from each method was thematically analysed and the findings integrated.

Firstly, methodologically the internet medium was found to be a valuable additional tool for accessing rich illness experiences. Further, the essence of the RSI experience was conceptualised as being pervaded by uncertainty and involving major life changes in people's employment, social participation and ability to perform routine daily activities such as caring for themselves, family members and the home. Also changed were sufferers' identities, financial circumstances and relationships both in and outside of work. RSI was found in this study to bear the hallmarks of a chronic pain condition with attendant implications for management and diagnosis.

In this study, the significance and meaning of a medical diagnosis was found to extend far beyond establishing 'what was wrong'; it became a quest for evidence to support the reality of participants' suffering, a means of defending threats to their integrity and identity and an essential requirement for certain forms of support.

The implications of these findings are discussed in the context of current chronic pain management which places less emphasis on finding a diagnosis and greater emphasis on restoring functioning and reducing disability on the premise that regardless of aetiology, the problems encountered are similar across different chronic pain conditions. However, this study suggests that the significance of a diagnosis should not be under-estimated since it carries multiple meanings for sufferers and its lack can have profound consequences for their daily lives.

## **Keywords**

Repetitive Strain Injury (RSI), Upper Limb Disorders (ULDs), qualitative research, illness experience, healthcare research, internet research, online focus groups, e-mail analysis.

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# 1 Study aims and background

## 1.1 Introduction to the study

Repetitive strain injury (RSI) is an important and costly social, occupational and health problem and causes considerable human pain and suffering to individuals and their families. Moreover, it has important economic significance in terms of lost productivity, sickness absence, and compensation and places a large burden on health care resources, such as health professionals' time, medical interventions and tests (Gauthy, 2007).

The UK Health and Safety Executive (HSE) statistics for 2006/7 estimate the UK prevalence of RSI to be 426,000. More significantly, HSE statistics for 2005/6 indicated that whilst back pain incidence appeared to be decreasing, new cases of RSI now exceeded those of back pain. These figures refer to self-reported cases of RSI based on people who believe they have it, and are shown in Table1.1.

**Table 1.1: Self-reported prevalence and incidence figures for RSI in the UK from 2004 to 2007**

<b>Year</b>	<b>2004/5</b>	<b>2005/6</b>	<b>2006/7</b>
<b>Number of overall RSI cases in UK (prevalence)</b>	375,000	374,000	426,000
<b>New cases of RSI in UK (incidence)</b>	93,000	86,000	115,000

Our current knowledge of RSI is limited compared to other musculoskeletal conditions (Burton et al, 2008). Therefore, a better understanding of the personal experience of RSI from the individual's perspective is clearly beneficial, both economically and socially. Knowledge about how people manage RSI in their daily lives and what they think and do may be helpful in devising strategies to rehabilitate people back to work and other productive activity. The value of 'lay' experiential

knowledge has already been successfully demonstrated in the USA and in the UK's NHS Expert Patient Programme (Department of Health, 2001; Taylor and Bury, 2007). Sufferers' experiential knowledge is also valuable in enabling health professionals to 'vicariously experience' what their patient's life is really like.

### **1.1.1 Aims of the research**

In the context described above, this research set out to answer the question: 'What is the personal experience of living with RSI like and what can we do with this information to improve outcomes of treating and managing RSI?'

Hence, this study aims to:

- gain a deeper understanding of the experience of having one of a range of conditions covered by the term repetitive strain injury (RSI);
- assess the utility of recently developed methods, such as internet focus groups in achieving valid research aims.

The research study is presented in this thesis in two main sections:

Chapters 1 – 6: The introduction, background and literature reviews of relevant areas

- Chapter 1 Study aims and background.
- Chapter 2 Literature review - Pain.
- Chapter 3 Literature review - Current knowledge of RSI
- Chapter 4 Literature review - RSI disability, management and rehabilitation.
- Chapter 5 Literature review - Illness experience research.
- Chapter 6 Literature review - Internet research

Chapters 7 – 11: Methodology, research study methods, findings and analysis, reflection on the study and conclusions

- Chapter 7 Methodology, providing the theoretical underpinnings for the research study



- Chapter 8 Methods, findings and discussion for analysis of support group e-mails
- Chapter 9 Methods, findings and discussion for online focus groups
- Chapter 10 Integrated findings and analysis from the two different phases of the study
- Chapter 11 Conclusions, research contribution and further research.

## **1.2 Overview of RSI**

### **1.2.1 Definitions: Diagnosable and non-diagnosable forms of RSI**

The term 'RSI' encompasses disorders which are diagnosable and, therefore, clinically accepted as they have a clear identifiable pathology (for example carpal tunnel syndrome), and disorders which are contested because they are not accompanied by any clinical signs of disease (termed non-specific, diffuse RSI). In this study, RSI is taken to include both clinically defined medical conditions and non-specific, diffuse RSI. Some of the terms used synonymously with RSI include work related upper limb disorder, cumulative trauma disorder and occupational over use syndrome. A full list is provided in chapter 2.

### **1.2.2 Terminology**

In this study, people who have RSI have been referred to as 'RSI sufferers' for the pragmatic reason of minimising wordage and to avoid the unwieldy phrase 'individuals who have RSI'. It is also the term suggested by Conrad in place of patients since ill people only spend a short amount of time in the patient role (1990). The term RSI sufferer has also been used by other authors writing on the personal experience of RSI.

### **1.2.3 RSI - a growing international occupational health problem**

Upper limb disorders affecting the hands, arms and neck – which together have been informally grouped as RSI – and back pain constitute around 80% of conditions collectively termed musculoskeletal disorders (MSDs) which are often associated with the workplace. The rapid introduction of modern information technology and work practices has seen RSI develop into a major global

occupational health problem (Dembe, 1999; Buckle and Devereux, 1999). Current scientific knowledge and understanding of RSI is limited (Willis, 1986; Buckle and Devereux, 1999) and its management poor (Littlejohn, 1995, Konijnenberg et al, 2001), often resulting in frustration and dissatisfaction for sufferers. Rising trends in the use of technology are likely to exacerbate the problem as workers become more exposed to risk factors (Buckle and Devereux, 1999).

RSI occurs across many different sectors of the workforce including construction workers, process workers, tool operators, the textile, agriculture and food industries, musicians and computer users (Walker, 1979; Fry, 1986; Mullaly and Grigg, 1988; Gerr et al, 1991; Reid et al, 1991; Sluiter et al, 2001). RSI affects both sexes, although it is believed to be more prevalent among women. It has also been found in children (Alexander and Currie, 2004).

Various countries around the world have reported large numbers of RSI cases. The most well documented is the Australian 'RSI epidemic' of the 1980s, but 'outbreaks' have also been reported in the Far East, America (Katz et al, 2000) and Europe where it is now described as a 'pandemic' by the European Trade Union Institute (Gauthy, 2007).

#### **1.2.4 Growing RSI concerns across Europe**

In 1998, the European Commission established the European Agency for Safety and Health at Work to encourage coordinated efforts to improve knowledge and understanding of common occupational health problems and to find joint solutions. This body commissioned research to establish the extent of the RSI problem across member states of the European Union. The remit included conducting a review of the available scientific knowledge regarding risk factors for work-related neck and upper limb disorders (WRULDs) and evidence for work causation. This research information project was conducted by Buckle and Devereux (1999).

The research findings were presented in a report entitled *Work related neck and upper limb musculoskeletal disorders* published in 1999 which concluded that due to the lack of standard criteria for assessing WRULDs across member states, it was difficult to draw comparisons and hence assess the true extent of ill health and

associated costs. Despite these difficulties, the report claimed there was ‘substantial evidence that neck and upper limb musculoskeletal disorders were a significant problem with respect to ill health and associated costs within the workplace.’ The report further predicted that the problem would likely increase as more workers became exposed to workplace risk factors for these disorders.

In the UK, MSDs (mainly RSI and back pain) have become a priority for the UK's Health and Safety Executive. The Executive launched a campaign in June 2005 to raise awareness of MSDs and specific targets have been established to achieve a significant reduction in the numbers of individuals affected by MSDs by 2010.

### **1.2.5 Costs of RSI**

#### *1.2.5.1 Economic costs of RSI*

RSI represents a huge socio-economic cost to society. MSDs (principally back pain and RSI) are the most common cause of occupational ill health in Great Britain, affecting 1.2 million people and costing society over 200 million pounds annually for RSI alone (HSE Press Release, 2002). MSDs also cost US companies billions of dollars each year (Turk and Rudy 1992). Recruitment and re- training further elevate these costs according to Cherniack, (1996). These figures highlight that RSI is an economically significant global problem that needs to be better understood.

#### *1.2.5.2 Socio-economic costs of RSI*

RSI also places a large financial burden on health service resources. Gauthy, (2007) reported that across Europe approximately 15%–20% of primary care consultations were related to MSDs and that MSDs were the main reason for early retirement due to ill health. Studies in the USA showed that medical care is sought more frequently and for a longer period with RSI than with other types of occupational injury (Katz et al, 2000). In addition, within the health care setting, RSI can be a source of

frustration for some health professionals as it is frequently characterised by pain that is unresponsive to standard treatments so that whilst medical help is frequently sought, it is often ineffective (Littlejohn, 2007).

#### *1.2.5.3 The human suffering caused by RSI*

At the individual level, RSI has the potential to affect people's everyday lives adversely through job loss, financial hardship and strained relationships (Gauthy, 2007). The pain and discomfort which accompanies and characterises RSI can develop into a long-term condition. Gauthy, (2007) stated that joint pain, especially when it occurred on movement, led to impairment in motion, leaning, grasping and other functions causing incapacity to work normally. Work incapacity could carry over into other life spheres, such as reduced or complete inability to carry out activities and movements of daily life. In the workplace, this could mean temporary or permanent job loss with a corresponding loss of livelihood; unemployment; early ill-health retirement if the worker cannot be redeployed or reassigned to work; being pensioned early due to permanent loss of work capacity; and conflicts with employers over a disputed causal link with work (Gauthy, 2007). Working for many people is an integral part of their normal social role and forms a part of their identity as well as a main source of income (Blustein, 2008). RSI can deny this basic need to work through limiting people's ability to function 'normally'.

A better understanding of RSI is clearly beneficial, economically and socially. This knowledge may also be valuable when devising strategies to rehabilitate people back to work.

#### **1.2.6 Current management of RSI**

Current management of RSI is described as poor (Littlejohn, 1995; Cohen, 2004), but agreement exists that optimal solutions for its prevention, medical management and the delivery of health care systems must be found (Katz et al, 2000). RSI sufferers who seek medical help are ideally placed to comment on current management practices and how these could be improved. The reportedly poor management of RSI is partly attributed to its complex nature, limited scientific knowledge and a general lack of understanding about RSI and of chronic pain

mechanisms in general (Feuerstein et al, 1993). Furthermore, in addition to the clinically recognised upper limb disorders (such as tenosynovitis and carpal tunnel syndrome), RSI includes a constellation of medically contested disorders which often lack clinical signs of pathology and therefore have an uncertain status in biomedicine. Within the traditional biomedical model, disease is treated or managed according to the presenting clinical signs which are problematic for individuals with non-specific arm pain who have subjective symptoms of illness but no clinical signs of disease (Winspur, 2001). Several other conditions have similar subjective symptoms which are unaccompanied by clinical signs, such as fibromyalgia (FM), chronic fatigue syndrome (CFS) and irritable bowel syndrome (IBS). These have been collectively labelled as medically unexplained symptoms (MUS) (Nettleton, 2006). Musculoskeletal conditions such as FM and CFS share many similarities with RSI, with Littlejohn, (1995) arguing that RSI is a regionalised form of FM. This aspect of RSI is discussed in full in Chapter 4 of this thesis.

### **1.2.7 RSI is preventable**

Some commentators believe RSI is largely preventable (Piligian et al, 2000; Hutson, 1999). Current literature on RSI suggests that the occurrence of RSI can be reduced or prevented through better information, education and utilisation of good working practices, workplace surveillance and the rapid treatment of initial symptoms (Buckle and Devereux, 1999; Gauthy, 2007). Given that RSI is considered preventable, more research and understanding of RSI could help inform strategies to reduce its incidence and to develop effective rehabilitation programs.

### **1.2.8 The need to understand the patient's perspective**

Whilst large scale epidemiological studies are essential for establishing the magnitude and variability of a condition in the population and for planning health care resources, they do not provide understanding or insights into what it is like to have an illness such as RSI from the individual person's or 'insider's perspective' (Conrad, 1990; Armstrong, 1990).

There are many valid and compelling reasons for studying and understanding the patient's perspective on illness, primarily because the illness experience relates to the everyday practical ways in which people live with and manage disease in their daily lives which is quite distinct from the biomedical conceptualisations of disease (Idler, 1979; Toombs, 1993; Radley, 1994). There is a plethora of literature on the perceived disparity between how health professionals and their patients think about illness and disease (May et al, 2000). Therefore understanding people's subjective experience of illness is important since it influences clinical outcomes (Epstein et al, 2003). Griffiths et al, (2006) stated that uncertainty in health care arose partly because health professionals had to apply medical evidence and knowledge derived from general population studies, such as clinical trials and epidemiology, to advise and treat individual patients, suggesting more studies of individuals are needed.

In addition, the patient's perspective has become more central in health care research from the growing need to close the gap between health care provision and patients' needs (Hyden, 1997; Lehoux et al, 2006; Lawton, 2003; Sullivan, 2003). This goal makes it important for health professionals to know and understand what the experience of illness is like for their patients. It is argued that if clinicians can better understand the lived experience of their patients, they can be more conscious of their needs and hence respond in a more effective, empathic and compassionate manner (Charon, 2001; Cook et al, 2001; Strong et al, 2006). Furthermore, a better understanding of the difficulties people face in managing and living with chronic illness can also shed light on factors which hinder clinical management (Strauss, 1990). Gerhardt, (1990) argued that first hand knowledge about the way people lived their lives with chronic illness could help make doctors more aware of their patients' life style and of the problems patients encountered in their daily work and home lives. Such knowledge (if available) she continued, would enable doctors to gauge the effectiveness of their clinical interventions and better customise treatment and advice so that it is more consistent with their patients' everyday reality (Gerhardt, 1990). It has also been suggested that medical students and doctors should read literary accounts of illness, pain and death as a way of developing empathy and compassion towards patients and to become more sensitive to the human dimensions of the illness experience (Lupton, 2003).

Either way, it is difficult to argue with Epstein et al's (2003) view that three very good reasons for understanding patients' accounts of illness are improved clinical outcomes, patient satisfaction and cost. Furthermore, increasing knowledge and understanding of patients' personal experiences can help bridge the disparity between the provision of health care and patients' needs.

### **1.3 Qualitative research: a different way of 'knowing'**

Accessing and understanding the patient's perspective requires a fundamentally different way of 'knowing' to that traditionally used in medical science (Malterud, 2001). Qualitative research can provide theoretical insights not accessible through other approaches that describe and explain phenomena such as people's experiences, interactions, roles and perspectives (Cook et al, 2001). Particular strengths of the qualitative approach is its ability to access the minute detail which comprises the patients' experience and meaning of illness, and in providing insights into factors which may exist outside the clinical purview (Armstrong, 1990; Murphy et al, 1998). Studying peoples' accounts of their illness provides researchers with an unrivalled means of understanding people's illness related problems and concerns in a holistic way (Greenhalgh and Hurwitz, 1999). Through such detailed accounts of people's illnesses, health professionals and others can "live through" and vicariously experience what the lives of patients are really like (Greenhalgh and Hurwitz, 1999). This compatibility between qualitative approaches which aim to understand people's subjective experiences makes it highly congruent with the research aims of this study which aims to understand the experience of RSI from the perspective of those who have it. Having established the benefits of understanding people's experiences and a suitable research approach for achieving this, an important consideration is the practicality of accessing patients' illness experiences.

#### **1.3.1 Solving some of the problems associated with accessing patients' experiences**

The experience of illness is a highly significant and personal event, which often disrupts people's lives, relationships and identities (Bury, 1982; Charmaz, 1983). It

is also an intensely social experience rousing deep emotions which people need to understand and make sense of through sharing their experiences and seeking the opinions of others (Radley, 1994; Davison et al, 2000). Recounting illness experiences enables people to give meaning to their illness, and permits them to put their illness into context and perspective (Greenhalgh and Hurwitz, 1999; Mattingly and Garro, 1994, 2000). Traditionally such illness related concerns have been discussed informally with family members, friends, and work colleagues or more formally with health professionals (Cotton and Gupta, 2004). However, as Petrie and Weinman, (1997) point out, there are practical difficulties in gaining access to this private, informal talk between people about their illnesses. Clinical settings such as rheumatology or back pain clinics have been extensively used by researchers to recruit study participants to access such experience. However, such 'over reliance' on the clinical setting has drawn criticism from authors such as Conrad, (1990) and Thomas and Johnson, (2000) since this already biases the sample to those who seek medical help for their illness and excludes those who do not (Conrad, 1987; 1990). Moreover, Conrad encouraged researchers to recruit participants from non-clinical settings such as their work and home, since health care is only one aspect of illness (Conrad, 1987).

The internet provides one potential solution for researchers wishing to access and understand illness experiences since it has opened up new venues for social interaction where people can meet to discuss and share their illness experiences, such as online disease-specific patient support groups (Davison et al, 2000). The potentially rich data in this new medium has encouraged researchers to venture online to both collect and generate data resulting in a proliferation of online studies. The studies discussed later in this thesis demonstrate ample evidence of the highly personal and rich data which can be generated online.

As we have noted, qualitative research is eminently suited to accessing such patients' insider perspectives which focus on the subjective experience of living with and in spite of illness (Conrad, 1987). In support of this paradigm, the internet has created unprecedented opportunities for researchers to access data on people's illness experiences. The relative newness of this methodological approach and the accompanying complex ethical issues are addressed in Chapter 7. Using this new internet methodology the illness experience of musculoskeletal conditions such as



back pain, chronic fatigue syndrome and fibromyalgia have already been investigated, but to date no such study of the experience of RSI has been conducted.

#### **1.4 How this study will contribute to existing knowledge**

As we have established, the literature suggests that RSI is a significant health and occupational problem. However, to date, few studies have investigated the personal experience of RSI. Authors such as Reid et al, (1991) and Dorland and Hattie, (1992) have argued that subjective studies of people's experiences of RSI have been largely ignored. Current literature supports this view since there are still very few qualitative studies which have taken a holistic view of the experience of RSI. Moreover despite the recent online research on other contested illnesses such as back pain, chronic fatigue syndrome (CFS) and Fibromyalgia (FM), no similar internet based research has been conducted on RSI.

Unlike most previous studies, this study will investigate the experience of having RSI in both men and women. Previous studies have focused predominantly on women's experiences with little reported about the male perspective of having RSI, so this study will help address a gap in our current knowledge. As seen earlier, a better understanding of people's experiences of living with and managing RSI can help sensitise health professionals to the reality of their patients' lives, enabling health professionals to direct their interventions and care accordingly.

A further contribution of this study is that it will access RSI sufferers' experiences using developing internet methodology to collect and analyse pre-existing qualitative data from archived e-mails and to generate new data through interactive online focus groups. No internet based study of RSI experiences has been conducted to date. In addition, this developing methodological approach provides an opportunity to assess the utility of such online methods and some of the issues surrounding such developing methods. With these issues in mind, the study was designed to achieve a number of key aims, which were detailed earlier in this section.

## **1.5 Summary of this chapter**

This chapter highlighted the importance and social relevance of this study to investigate the experience of RSI, provided an overview of the thesis layout and set out the aims and objectives of this study. Important messages are that RSI is a little understood yet growing health and occupational problem that warrants further research. The confusing term 'RSI' encompasses both conditions that can be diagnosed and are medically accepted, such as carpal tunnel syndrome, and disorders that are defined as diffuse non-specific arm pain, for which no pathology is usually evident. In this study, both clinically recognised disorders and diffuse non-specific arm pain are studied, but it is individuals with diffuse non-specific arm pain who encounter most difficulty in obtaining a diagnosis and form the focus of much of the controversy surrounding RSI. Accessing patients' illness experiences can sensitise health clinicians to patients' lived reality enabling them to provide more effective clinical care and management.

The next chapter focuses on pain which is a key aspect of understanding the experience of RSI since it is a primary presenting symptom which prompts medical help seeking and accounts for much of the distress and disability observed in individuals with RSI.

## **2 Chapter 2 Pain: its role, definitions and mechanisms**

### **2.1 Aims of this chapter**

As seen in the introduction, RSI can cause considerable human suffering and disruption to people's lives (Bammer and Blignault, 1988; Arskey, 1998; Reid et al, 1991). Much of this disruption is attributed to the experience of pain which is a primary presenting symptom in RSI (Piligian et al 2000; Lynn, 2006; Sluiter et al, 2001; Hutson, 1999; Burton et al, 2008). Pain associated with RSI can become chronic and debilitating and prevent sufferers from working and intrude on all aspects of their lives (Hutson, 1999; Reid et al, 1991; Arskey, 1998; Burton et al, 2008). Given the pervasive role of pain in RSI, it is necessary to understand its nature and complexity as background to understanding its impact on people's experience of RSI.

This chapter, therefore, looks at historical and contemporary models used to explain mechanisms for pain perception including Dualism, Gate Control Theory (GCT), Neuromatrix theory and Neuronal Plasticity. It provides definitions of acute and chronic pain emphasizing the important distinctions between them, explains the classic view of the role of pain as a basic survival mechanism elicited in response to tissue damage/injury and shows how chronic pain challenges this deep seated view. Also discussed are the psychological, social and cultural factors which influence an individual's perception and experience of pain, since pain is subjective and interpreted differently by everyone (Skevington, 1995; Eccleston, 2001).

### **2.2 Scope of the literature review**

The literature on RSI was accessed from searching electronic databases and through identifying further literature listed in key research articles. Grey literature such as reports published by the Health and Safety Executive, Department of Health, European Health and Safety Commission and ethical guidelines were found using general internet searches. A systematic literature search of Medline, CINAHL, PsychInfo, SSCI, and Cochrane Database was conducted covering the period 1990-

2007. Mesh terms used to identify relevant articles included, RSI, cumulative trauma disorder, (work related) upper limb disorders, and upper extremity disorders. Terms used for illness experience literature were illness experience, personal experience of illness and qualitative research. The majority of the literature review is based on scientific journals but some earlier work published in textbooks in anthropology and medical sociology was also used. Most of the studies on illness experience were found in the Social Sciences literature, but Psychology and coping based studies which focused on the impact of illness on self, identity and acceptance are also included due to their significance in illness experience. Literature in Health Sciences was also consulted together with literature in occupational medicine and rehabilitation. The majority of the literature emanated from the UK, North America, the Scandinavian countries and Australia and was restricted to articles written in English. It was not feasible or practical to review the large number of studies cited. Therefore Boolean characters were used to narrow the focus of the topic to the experience of RSI and the experience of illness in working age adults, by for example excluding studies of children or only older people, detailed clinical studies of particular types of specific disorders and the experience of cancer. Titles and abstracts were used to make decisions regarding relevance to the study and whether or not to obtain the article. Several topics and conditions were excluded e.g. studies on diabetes and respiratory conditions, as the aim was to focus on musculoskeletal disorders rather than all illnesses which would have been too broad. The main emphasis was placed on qualitative studies on insider's perspective of illness.

## **2.3 Models for understanding pain perception**

### **2.3.1 Early theories: Descartes' Model and the Specificity Theory**

A highly influential early model for pain perception was Descartes' stimulus-response model in which pain was considered to be a sensation (Melzack, 2003; Main and Spanswick, 2000; Ogden, 2000). Descartes' diagrammatic representation described pain within a biomedical framework interpreting it as a reflex action in response to a painful stimulus (Melzack, 2003; Main and Spanswick, 2000). It

illustrated how pain helped avoid or limit damage to the body through a natural reflex response action, such as by withdrawing a part of the body ( e.g. a foot ) from a painful noxious stimulus (e.g. a fire) (Melzack, 2003). An important assumption inherent in this model was that the mind and body were separate processes, termed dualism (Bendelow, 1993). A major criticism of this model was that it focused almost exclusively on the transmission of messages from the skin to the brain and failed to consider how nerve impulses were transformed in the brain into the subjective experience of pain, such as its perceptual qualities and the emotions and meanings attached to pain (Melzack, 2003).

Descartes' model was later developed into the Specificity Theory of pain by suggesting the presence of specific skin receptors which transmitted touch, warmth and pain (Main and Spanswick, 2000). However, limitations of both these early models of pain perception included their:

- Assumption of a one-to-one relationship between tissue damage and pain experience;
- Focus on physiological aspects of pain rather than its perception;
- Classification of pain as either organic or genuine (if visible evidence of injury was present), or psychogenic (if visible pathology was absent);
- Discounting of psychological factors such as anxiety and fear as being a consequence of pain rather than a contributory factor in pain.

(based on: Main and Spanswick, 2000; Melzack, 2003; Skevington, 1995).

A result of the focus in these early models was that the importance of the role of psychological factors in pain perception only emerged later following three key observations (Ogden, 2000; Butler and Moseley, 2003; Melzack, 2003):

- Acute pain was responsive to medical treatments but chronic pain was not, suggesting factors outside the direct pain-response models were involved;
- Beecher's (1956) observations that soldiers and civilians exposed to similar injuries experienced markedly different levels of pain which he attributed to pain perception and the meaning of the injury/wound within the pain experience. Pain in wounded soldiers was mitigated by the euphoria of being removed from the battle field and hence the risk of harm or death;

- Phantom limb pain was experienced by some people with an amputated limb or those born with missing limbs, but not by all amputees and considerable variability in the pain experienced was observed.

These observations highlighted the variability in pain perception between individuals, that pain could occur without evidence of tissue injury and its effect could be mediated by psychological factors, suggesting the pain mechanism to be more complex than prevailing models suggested.

### **2.3.2 Gate Control Theory of Pain Perception**

The challenge of explaining this individual variability in pain perception was taken up by Melzack and Wall who in 1965 published Gate Control Theory (GCT) which incorporated the psychological, (emotional and cognitive) components of the pain experience (Skevington, 1995). GCT posited that pain was a multi-dimensional phenomenon and that its perception was based on a complex nervous system. GCT drew on concepts from neurophysiology, psychology and on clinical observations of patients' experiences to explain pain variability (modulation) between individuals (Main and Spanswick, 2000). GCT proposed the existence of a gate-like mechanism located in the dorsal horn whose opening and closing was controlled by inputs received from both peripheral and central sources. The more the gate is opened, the greater the perception of pain resulting from signals arriving at the cortex and vice versa. The gate received inputs from activated peripheral nerve fibres at the source of tissue damage/injury about noxious stimuli such as heat, pressure and chemicals via the small nerve fibres (A-delta and C-fibers) which opened the gate to allow nociceptive signals to pass to the brain. The gate also received information from large fibers (A-beta) fibers which carried information about touch (pressure) which closed the gate, preventing the transmission of messages to the brain. Descending central inhibitory messages from the brain about the person's emotional state were also factored into the gate mechanism (Main and Spanswick, 2000). Inputs from both peripheral and central sources were then combined to produce a final output from the gate which sent information to an action system resulting in the individual's perception of that stimulus as pain. Factors contributing to the opening or closing of the gate (and hence pain modulation i.e. the experience or absence of pain), included physical injury or activation of the large (touch) fibres; emotional factors such as happiness, optimism, relaxation, anxiety, fear, negative beliefs,

expectations and behavioural factors, such as concentration, or distraction through involvement in other activities (Ogden, 2000). GCT highlighted the complex multi-dimensional nature of pain perception and how many factors contributed to the overall experience of pain.

### **2.3.3 Contributions of GCT to pain understanding**

GCT improved pain understanding by providing a mechanism for the transmission and modulation of nociceptive signals which could explain pain variability and could be tested (Strong, 1996). Pain perception was shown to result from complex interaction of physiological and psychological factors and was not only a response to sensory information. This was instrumental in transforming the way pain perception was conceptualised from only being a sensation to being a perception and an experience.

A major contribution of GCT was that it directed research attention to the role played by psychological (emotional and cognitive) factors in pain perception (fear, anxiety, beliefs about pain, appraisal of pain, coping and depression) (Eccleston, 2001; Main and Spanswick, 2000; Strong, 1996). Such psychological factors have become important in the understanding and management of pain and are considered next.

## **2.4 Psychological factors in pain perception, maintenance and disability**

Psychological factors play an important role in chronic pain disability, how people cope with pain, their quality of life and in the transition from acute to chronic pain (Turk and Okifuji, 2002). Health professionals observed that the levels of pain and disability reported in chronic pain patients were often disproportionate to the amount of damage or disease (Eccleston, 2001). Patients with widespread damage and pain may report little disability whilst others with comparatively minor damage and pain may report widespread disability, suggesting pain was not a reliable measure of tissue damage and other factors were involved (Eccleston, 2001). Researchers sought to account for these differences in people's response to pain. Explanations

proposed included the mediating effect of psychological factors, beliefs about pain, gender and age, culture and differences in personality, which are considered next.

## **2.5 The plasticity of the nervous system**

One of the most significant advancements since the GCT has been the theory of nerve plasticity (Dubner, 1997). This provided for an altogether more flexible sensory system which could be modified by tissue damage but also by factors such as emotions and memory (Dubner, 1997; Woolf and Salter, 2006). The nerve plasticity theory suggests that parts of the body are represented at four levels in the central nervous system; the dorsal horn, the thalamus, the limbic system and the cortex, each of which is capable of undergoing neural plasticity changes. Pain chronicity is related to the sensitisation of neurones and synapses at these different levels. Nerve sensitisation can be both peripheral and central. In peripheral sensitisation, tissue injury causes electrical activity at nociceptors but it may also cause increased sensitivity of the nociceptors at the site of injury after injury. Furthermore there is evidence that 'silent' nociceptors which are normally 'dormant' become activated after tissue injury, which is termed allodynia (Main and Spanswick, 2000). Hyperalgesia refers to an exacerbated pain response to a mildly painful stimulus (Basbaum et al, 2005). Such states are important in non specific RSI and other chronic pain syndromes.

## **2.6 Central sensitisation**

Central sensitisation refers to functional changes in the spinal cord and brain as a result of increased neuronal stimulation which contribute towards hyperalgesia and spontaneous pain (Main and Spanswick, 2000). The consequences of this enlarged receptive field and peripheral and central sensitisation are the amplification of nociception signals and to painful experiences from non-nociceptive stimuli which would not normally be painful.



## **2.7 Neurological basis for non-specific RSI**

The peripheral and central sensitization discussed above is commonly observed in people with non specific RSI, suggesting increasingly that it has a neurological basis (Hutson, 1999; Cohen, 2004; Lynn, 2006). Hutson (1999) suggested using the term 'neuropathic arm pain' for non specific RSI since this reflected its pathogenesis. Central sensitization, nerve tenderness at several sites and areas of hyperalgesia or allodynia are often observed in RSI patients (Lynn, 2006; Cohen, 2004). According to Lynn (2006) non specific RSI resulted from a combination of minor peripheral nerve damage, physiological factors such as central sensitization and behavioural factors. Hutson (1999) stated that the peripheral and central neurosensitisation seen in RSI arose from soft tissue injury or inflammation in the neck or arms which stimulated nociceptive unmyelinated primary afferents. Somatic disturbances such as joint strain, tendon micro trauma and muscle fatigue, neural dysfunction in the spine or peripheral nerve irritation could all lead to tissue injury in non specific RSI (Hutson, 1999). Furthermore the over stimulation of the spinal cord by nociceptive inputs in some people with RSI could lead to increased sensitization which increased excitability of the wide dynamic range neurones (WDR) in the dorsal horn which is then maintained by neurotransmitters released from nociceptive C and A fibres (Hutson, 1999; Cohen, 2004). Also common in non specific RSI is wind-up (increased response to repeated stimulation) and hyperpathia (prolonged response to afferent stimulation) (Hutson, 1999). These processes help explain the pain amplification and persistence of pain observed in non specific RSI. It is believed that non specific RSI is reversible in the early stages but can become long term and increasingly compromise people's ability to work and intrude on their recreational and domestic activities (Hutson, 1999). Psychological symptoms such as depression and distress which may accompany RSI can further exacerbate pain and disability (Hutson, 1999). These are important factors in understanding the experience of RSI related pain symptoms.

## **2.8 The Neuromatrix Theory**

Melzack's (1999) Neuromatrix theory of pain is an advancement of the GCT which arose from research to explain how phantom limb pain can be experienced in the absence of nociception, for example in a limb which no longer exists. The

Neuromatrix theory holds that pain is a multi-dimensional experience produced by characteristic 'neurosignature' patterns of nerve impulses generated by a widely distributed neural network called the 'body-self neuromatrix' in the brain which itself is modulated by sensory inputs, the body's stress system and cognitive functions of the brain. The resulting output patterns of the body self neuromatrix, the neurosignature then activate perceptual, homeostatic, and behavioural programs after injury, disease or chronic stress. Both sensory and non sensory inputs meet at the neuromatrix to produce the output pattern of nerve impulses or neurosignature (Melzack, 1999).

The neuromatrix theory highlights the complex and multi-dimensional nature of pain, suggests how pain can be experienced in the absence of sensory stimulation/tissue damage such as in an amputated limb and introduces the role of stress as a mediator in pain.

These models to explain pain perception have highlighted the complexity of pain and have influenced the way we think about and define pain which is considered next.

## **2.9 Pain: a private subjective phenomenon**

Whilst pain is ubiquitous and experienced by almost everyone, it is also uniquely experienced by each individual, rendering it both a public and private experience (Scarry, 1985; Turk and Rudy, 1992; Toombs, 1993). Pain symptoms are often internal, invisible and cannot be observed by others (Idler, 1993). This inaccessibility of pain to others and its 'unshareability', make it an experience known only to the individual (Toombs, 1993; Melzack and Wall, 1996). Individuals learn the meaning and use of the term 'pain' through injuries experienced during childhood (Merskey et al, 2005). Moreover, pain is a difficult experience to translate into words. Authors such as Sontag (1989) and Rose (1994) have stated that invisible pain can often only be described metaphorically e.g. "stabbing like a knife," since merely saying "it is painful" could not express the feeling of pain. Le Shan (1964) stated that sometimes a scream was the only way to express pain since words were insufficient and compared long-term pain with living a nightmare. This private pain and suffering

may lead individuals to feel isolated, especially if no organic cause for pain is found (Eccleston, 2001; Nettleton, 2006). For some people, pain can become so unbearable as to drive individuals to contemplate and commit suicide (Melzack and Wall, 1996; Hitchcock et al 1994). The subjective nature of pain is important in non specific RSI where pain symptoms occur in the absence of pathology meaning individuals experience illness in the absence of disease or injury.

## **2.10 Defining Pain**

Given the complicated nature of pain, defining pain is no easy task. Bonica (1990) called for a standardised classification of pain, but acknowledged it would be a challenge to find a concise definition of a condition which could incorporate its physiologic, pathophysiologic, psychological, emotional and affective dimensions. Moreover, such a definition needed to incorporate pain caused by both physical disorders and psychological factors ('organic' and 'psychogenic' pain). To its credit, the International Association for the Study of Pain (IASP) Task Force on Taxonomy (1994: 210) took up this challenge and produced a definition which has since been widely adopted. This definition of pain focused on pain perception and defined pain in terms of being a subjective experience (Anand and Craig, 1996; Loeser and Melzack, 1999; Merskey et al, 2005; Strong et al, 2002). The IASP definition of pain is:

“an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”.

The IASP definition acknowledged pain had both sensory and perceptual characteristics, was an unpleasant emotional experience and the association between pain and injury was not always direct (Eccleston and Crombez, 1999; Melzack and Wall, 1996). This definition also acknowledged that pain could occur without tissue damage or nociception (Strong et al, 2002). This is important because many doctors and patients alike failed to appreciate that pain could occur without nociception (Loeser and Melzack, 1999) which is highly important for understanding chronic pain conditions such as diffuse RSI.

## **2.11 Pain classification systems**

Merskey (1990) highlighted the pragmatic need for standardised classification systems in medicine. This has resulted in medical conditions being classified in various ways e.g. according to their underlying pathology, location in the body, whether pain is cancer-related or not, or based on the duration of the condition. Merskey (2007) commented on the unusual way RSI is classified stating “repetitive strain syndrome is diagnosed rightly or wrongly, on the basis of pain in parts which are overused” (Merskey, 2007:15). Of the various ways of classifying pain, one commonly used way is based on the duration of pain where pain is described as transient, acute or chronic. Differences between these terms are very important for conditions such as RSI and are considered next.

### **2.11.1 Transient pain**

Transient pain is very short term localised pain resulting from a minor injury to the body (such as a mild burn or a prick from a needle). This usually heals rapidly with little or no tissue damage (Melzack and Wall, 1996).

### **2.11.2 Acute pain**

Bonica (1990) defined acute pain as “a complex constellation of unpleasant, sensory, perceptual and emotional experiences and certain associated autonomic, physiologic, emotional and behavioural responses.” Everyday acute pain, or nociceptive pain, arises from a noxious stimulus on the skin or in deep tissue (Basbaum et al, 2005). Acute pain is characterised by tissue damage, pain and anxiety and is short term lasting from a few days to weeks depending on the extent of injury (Melzack and Wall, 1996; Loeser and Melzack, 1999). Most people will have experienced acute pain from cuts, burns, headaches or other pain making it a universal experience (Main and Spanswick, 2000; Loeser and Melzack, 1999). Acute pain after an injury or infection has important survival value in protecting individuals from actual or potential threats and in avoiding them in the future (Melzack 2003; Melzack and Wall, 1988 in Strong et al, 2002).

### **2.11.3 Chronic Pain**

In contrast to acute pain which has a survival value, chronic pain is destructive and appears to serve no useful purpose (Melzack, 2003). Bonica (1990) highlighted that acute and chronic pain differed fundamentally in aetiology, mechanisms, pathophysiology, symptomology, biological function and approach to diagnosis and therapy (Bonica, 1990). Since then, a significant milestone in the field of pain has been the recognition that chronic pain is a discrete phenomenon, different from acute pain (Merskey, 1990). The European Federation of IASP Chapters (EFIC) proposed that chronic pain should not be considered only as a symptom of injury or disease but should be accorded disease status in its own right (EFIC, 2001).

Whilst chronic pain may initially result from injury or disease, it is often maintained or intensified by factors other than the initial cause of the pain such as stress, affective and environmental factors (Loeser and Melzack, 1999).

### **2.11.4 Definition of chronic pain**

Initially chronic pain was defined as pain lasting more than 3-6 months but subsequently the IASP taskforce on pain taxonomy and others felt this definition based on duration and evidence of healing was inadequate (Brennan et al, 2007). Moreover, Loeser and Melzack (1999) argued that it was not the duration of pain that distinguished acute from chronic pain but more significantly it was the body's inability to restore its physiological functioning to normal homeostatic levels. The IASP Taskforce (1994) offered the following revised definition for chronic pain as:

“A persistent pain that is not amenable, as a rule, to treatment based on specific remedies, or to the routine methods of pain control such as non-narcotic analgesics.”

The emphasis in this definition shifted from a timescale for expected healing to pain that was unresponsive to normal means of controlling it.

These discussions reflect some of the difficulty in capturing the subjective and multi-dimensional nature of pain into a definition which adequately conveys its full meaning. For the purposes of this study, chronic pain is used with the general meaning of long-term intractable pain. Some key differences between acute and chronic pain have been summarised in Table 2.1.

**Table 2.1: Some key differences between acute and chronic pain**

<b>Characteristic</b>	<b>Acute pain</b>	<b>Chronic pain</b>
Role of pain	Pain is a symptom	Pain is the disease itself
Cause of pain	Pain usually results from injury, disease or infection	Pain usually begins with injury or disease but is subsequently maintained by other factors
Response to treatment	Responds to conventional pain treatments such as analgesics	Unresponsive to conventional analgesics, Tricyclic anti-depressants may be helpful
Role of psychological factors	Rarely due to psychological causes	Psychological factors important
Role of pain	Pain serves a protective biological function	Pain serves no apparent useful purpose
Approach to treatment	Recovery and cure	Recovery/cure may not be possible so symptom management and restoration of functioning become important
Role of psychological /social factors	Biological, social and psychological factors rarely maintain pain	Pain may be modulated and maintained by biological social and psychological factors

Table compiled from Strong, 1996; Melzack, 2003; Loeser and Melzack, 1999; Bonica, 1990.

### **2.11.5 Factors influencing the experience of pain**

Patients' beliefs about chronic pain, its onset and expectations of its persistence are important factors in influencing a patient's compliance with treatment and therefore are an important part of pain assessment and management (Williams and Keefe, 1991; Turk and Okifuji, 2002). Williams and Keefe (1991) showed that patients who believed their pain would persist, did not respond well to physical therapy or psychological interventions. This suggested that understanding patients' beliefs is

vital for ensuring that treatments provided were compatible with patients' belief structures (Williams and Keefe, 1991). The powerful belief that pain (hurt) equals harm is widespread in the population and presents a major challenge in pain management (Vlaeyen and Crombez, 2007). The association between pain and injury or harm is strong amongst people with RSI and measures are now being introduced to try to change this thinking (Burton et al, 2008). We now know that pain is a highly complex phenomenon whose presence is neither always beneficial nor indicative of injury which challenges traditional ideas about the relationship between pain and injury (Melzack, 2003). Some of these important factors in pain perception are considered next since they can interfere with patients' recovery.

#### *2.11.5.1 Pain catastrophizing*

Catastrophizing refers to an individual's exaggerated negative appraisal of a painful stimulation as being very catastrophic which can become dysfunctional long term and contribute to increased pain, disability and distress (Sullivan et al, 2001; Eccleston, 2001; Vlaeyen and Crombez, 2007; Severeijns et al, 2001). Such catastrophizing can lead to pain related-fear which includes the fear of pain, injury or activity in the belief that these will cause pain (Vlaeyen and Crombez, 2007). Catastrophizing is important because it influences help seeking behaviour such as the number of visits made to health professionals and medication use (Sullivan et al, 2001).

#### *2.11.5.2 Fear of pain and the fear avoidance model of pain*

Fear is a natural response to pain and the avoidance of pain inducing activities can be helpful in acute pain but such behaviour may exacerbate pain and be an obstacle to recovery in chronic pain patients (Turk and Okifuji, 2002; Vlaeyen and Crombez, 2007). The fear avoidance model of pain was developed to explain and predict the transition from acute to chronic pain disability (Vlaeyen et al, 2006). It predicted that patients who catastrophized about pain become fearful and adopted protective behaviours such as avoiding activities and paying more attention to symptoms, which impaired their physical performance and resulted in increased self reported disability (Vlaeyen and Linton, 2000). Fear-related behaviour is believed to lead to

hyper-vigilance, guarded behaviour, avoiding/escaping activities and muscular reactivity which maintain and amplify pain (Vlaeyen and Crombez, 2007). These behaviours are detrimental since they reduce involvement in productive activities such as work, leisure and social activities. Emerging evidence suggests that health care professionals may also unwittingly influence their patients' beliefs about pain (Coudeyre et al, 2006). The clinical implications of this pain-related behaviour are that those with such behaviours and who seem at risk of developing disability must be identified and treated early (Vlaeyen and Crombez, 2007).

#### *2.11.5.3 Coping*

The term coping can generally refer to anything a person does in response to a stressful event to eliminate or alleviate the stressor, regardless of its effectiveness, or it can mean a positive effect of removing the stressor or relieving the stress response (Eccleston, 2001). Pain induces a coping response which is considered to have a positive or negative effect on the individual and will depend on a variety of factors (Morley et al, 1999). How successfully people cope with pain will influence pain perception so is important in illness experiences such as RSI. Coping, it is argued, is generally an attempt to gain control over pain. However, acceptance theory considered next, challenges the utility of this interpretation.

#### *2.11.5.4 Acceptance in coping*

Acceptance theory is suggested as a potentially useful concept for understanding how people respond and adapt to pain (McCracken et al, 2004). It has also been shown to be a useful predictor of pain, disability, anxiety and physical and vocational functioning (McCracken and Eccleston, 2003). Acceptance theory advocates that patients remain active and engaged in meaningful activities of everyday living, despite pain (McCracken et al, 2004). McCracken et al, (2004) argued that activity is important and conversely passivity can be injurious to health and challenged the general contention that patients are unable to function while experiencing pain. They suggest a more successful approach to dealing with chronic pain involved relinquishing attempts to control pain believing it should be accepted as a part of



everyday life, since it is largely uncontrollable and that attention instead be focused on engaging in normal everyday activities (McCracken et al, 2004).

#### *2.11.5.5 Prior experiential learning and meaning of pain*

The intensity of pain experienced is influenced by previous pain experiences, the memory of pain and being able to understand the cause of pain and its consequences (Melzack and Wall, 1996; Skevington, 1995; Eccleston, 2001).

#### *2.11.5.6 Depression*

Depression can also influence pain perception and is common amongst chronic pain patients attending pain clinics and can be accompanied by feelings of anger, frustration and low self esteem (Eccleston, 2001). Anger in turn can have a negative effect both on health and treatment outcome and is seen as a way of patients claiming self control or self esteem (Fernandez and Turk, 1995). It is argued that whilst most adults who attend pain clinics have depression, this is not related to pain severity but rather to how the person reacts to the chronic pain (Turk et al, 1995). However, Gamsa (1994) stated that emotional disturbances seen in patients were more likely to be a consequence of chronic pain rather than a cause.

The importance of psychological factors in pain perception has had important implications for the clinical interventions used to manage chronic pain (Adams et al, 2006; Eccleston, 2001). Recognizing this differential in people's response to pain is considered vital for the successful management of chronic pain patients (Eccleston, 2001).

### **2.11.6 Effects of culture, gender and age on pain**

Cultural and social values influence the way individuals perceive and respond to pain (Morris, 1991; Melzack and Wall, 1996). Emphasizing the close association between biology and culture, Brennan et al (2007) stated that pain is constructed through both cellular mechanisms and wider cultural processes, with each culture

having particular attitudes to pain and its treatment. For example, ethnicity has been shown to influence the meaning given to symptoms, how they were labeled, communicated, who treated them, the type of treatment used, the expectations of the doctor-patient relationship and pain expression (Lipton and Marbach, 1984). In Zborowski's (1952) study which compared how Irish, Italian, Jewish and white Americans responded to pain, Zborowski found Jewish and Italian patients to be more emotional than Irish and white Americans who were more stoic.

#### *2.11.6.1 Influence of gender and age on pain*

Gender has been shown to influence pain perception with more female sufferers of chronic pain than men (Bendelow, 2000; Skevington, 1995). Unruh (1996) found women generally reported pain more often, the pain they reported was of a more serious type and persisted for longer than in men. However, she stated that women were more likely than men to have their pain attributed to psychogenic or psychological causes. Age is also believed to affect pain perception but currently little is known about the specific effects of particular age groups on pain perception (Eccleston, 2001). Skevington, (1995) pointed out that often gender, age and ethnicity were inter-related and difficult to disentangle.

### **2.11.7 Chronic pain epidemiology**

Chronic pain in RSI shares similarities with other chronic pain conditions and has been classed as a regional chronic pain syndrome (Littlejohn, 1995). As part of this larger group, chronic pain is a highly prevalent condition world wide which is challenging to manage as it is often unresponsive to treatments and affects people's health, health care services and society (Elliott et al, 1999; Smith et al, 2007; EFIC, 2001).

The combined effect of all these factors is that millions of people around the world suffer with unrelieved pain that is difficult to manage within the traditional biomedical model. Given this, the biopsychosocial is now gaining acceptance as the preferred model for managing chronic pain.

### **2.11.8 The biomedical model**

Conceptual models of illness are important and practically relevant because they influence how clinicians approach patients and the decisions they make about them (Engel, 1980; Wade and Halligan, 2004; Main and Spanswick, 2000). For example, assumptions inherent in the biomedical model include that illness and symptoms arise from a malfunctioning of the body or organs, emotional disturbances are separate from bodily disturbances and the patient is a passive recipient of treatment (Wade and Halligan, 2004). The biomedical model is more concerned with discovering disease pathology than on understanding illness (Wade and Halligan, 2004). It is the relationship between symptoms, signs and disease which guides doctors to search for physical signs of disease based on the patient's symptoms (Main and Spanswick, 2000). With this model, illness is assumed to be temporary, objectively measurable using diagnostic tests, and can be treated or cured with medical interventions (Engel, 1977; Main and Spanswick, 2000; Bendelow and Williams, 1995). However, illnesses which could not be explained using this model led to the emergence of the psychogenic view of pain and illness (Turk and Rudy, 1992; Wade and Halligan, 2004; Main and Spanswick, 2000). The biomedical model's inability to successfully manage chronic pain conditions where disease signs may be lacking, has led to growing acceptance of the wider biopsychosocial model of illness (Adams et al, 2006; Wade and Halligan, 2004; Burton et al, 2008).

### **2.12 The biopsychosocial model**

Engel (1977) stated that there was a need for a new, more inclusive scientific medical model believing medicine was in crisis because of its neglect of patients' and psychosocial issues. The biosychosocial model he proposed therefore is an extension of the existing biomedical model offering a broader framework for understanding illness and health by including biological, psychological and social aspects of illness together with patients' needs (Engel, 1977; Borrell-Carrio et al, 2004). It represents both a philosophy of clinical care and provides practical guidance for clinicians (Borrell-Carrio et al, 2004). This model acknowledged that

illness and suffering could not be explained based on physiological and structural aspects of human beings alone (Epstein et al, 2003). Rather it accepted that disease could occur without illness, illness without disease and suffering without illness or disease (Epstein et al, 2003). It recognized that beliefs, background, education, values, ethnicity, access to care and socioeconomic status may all contribute to a person's health. Whilst the biomedical model remains the dominant model for managing acute illnesses, it is considered inadequate for managing chronic pain which often lacks visible pathology which is the main focus of the biomedical model (Wall, 1999; Main and Spanswick, 1995; Wade and Halligan, 2004). The Clinical Standards Advisory Group (CSAG, 1999) report actively promoted the use of the biopsychosocial model by health professionals for the management of chronic pain and the World Health Organisation (WHO) revised disease classification system (WHO, 2001) is also based on a more inclusive biopsychosocial model of illness. More recently, Burton et al, (2008) have recommended the biopsychosocial model for the treatment and management of RSI type conditions.

## **2.13 Summary**

This chapter discussed what pain is, its definitions and models proposed to explain the mechanism of pain perception, highlighting its complex multi-dimensional nature. Also described was the beneficial role of acute pain in survival which was contrasted with the destructive presence of chronic long term pain which served no apparent useful purpose. Whilst acute pain can often be treated within the traditional biomedical model, chronic pain is now believed to be better managed within a broader biopsychosocial model taking into account psychological and social influences which are key components of the pain experience. Also covered were the importance of pain beliefs and psychological factors in pain perception. It was seen how research into phantom limb pain and other unusual cases of pain forced a re-evaluation of the assumption that pain is always beneficial and always arises from nociception or tissue damage. The resulting belief that 'hurt equals harm' is important for understanding people's experiences of RSI and other conditions.

Having gained an understanding of the complexity of pain, the next chapter examines our current state of knowledge about RSI from a medical, legal and social standpoint and discusses some of the many controversies which surround it. This background is important as it informs our understanding of how the individual experiences RSI.

## **3 Chapter 3: Understanding RSI**

### **3.1 Introduction**

Repetitive Strain Injury (RSI) is a complex condition characterised by pain and disability. Its complexity arises from the many controversies which surround it, including its terminology, definition, classification, epidemiology, pathophysiology, risk factors, legal implications, its contested biomedical status as a genuine medical condition and the extent of its work-relatedness. It is important to understand this background to RSI since these factors have a significant influence over sufferers' experiences of RSI, which is the focus of this study.

The term RSI was originally coined during the 1980s 'Australian RSI epidemic' (Gun and Jezukaitis, 1999). Dramatic increases in upper extremity cumulative trauma disorders (UECTDs) were also observed in America during the 1980s and 1990s (Keogh et al, 2000). Statistics published by the Bureau of Labour Statistics indicated that employers paid over \$15–\$20 billion in workers' compensation costs for these disorders annually (Department of Labour, 1999, in Keogh et al, 2000). These disorders also represented a major cause of lost-time injuries and resulted in prolonged incapacity amongst US workers. For people with carpal tunnel syndrome (CTS), the median time off work was 25 days, compared to 5 days for all other general illnesses and injuries (Keogh et al, 2000).

Given the considerable controversy over the 'RSI' label, it is useful to start by looking at definitions of RSI, given these can differ under different classification systems used in different countries.

### **3.2 Definitions and terminology relating to RSI**

In the UK, RSI refers to a wide group of musculoskeletal disorders affecting the neck, shoulder, forearm, elbow, wrist and hands (Arskey, 1998; Helliwell and Taylor, 2004; Buckle and Devereux, 2002; Bird, 2005). RSI affects tendons, nerves,

muscles, circulation, joint and bursae and can result in pain and impairment (Melhorn, 1998; Buckle and Devereux, 2002). The RSI Association reported that over 25 specific conditions were subsumed under this umbrella term. Many of these RSI conditions are accompanied by clinical signs and can be diagnosed through clinical examinations and tests and are accepted as medical conditions. However, approximately half the cases of arm pain do not have clear clinical signs or pathology and are consequently difficult to diagnose (Lynn, 2006). It is this latter group of non-specific diffuse arm pain which is usually controversial.

### 3.3 RSI: definitions and terminology

Despite much global debate on RSI or upper limb disorders, as yet, no consensus has been achieved on a standard meaning and definition of the term (Arskey, 1998; Crawford and Laiou, 2007). This lack of consensus for diagnostic criteria has hindered epidemiological efforts to establish RSI prevalence and causation (Helliwell et al, 2003). This is supported by an earlier review commissioned by the EU to determine RSI prevalence across Europe which concluded that a lack of standardised terminology had prevented the establishment of a coherent picture of RSI across Europe, making it difficult to find joint solutions to a common problem (Buckle and Devereux, 1999). Within the literature, RSI is referred to using a variety of terms such as those seen in Table 3.1 and new terms are periodically added such as ‘Upper Extremity Musculoskeletal Disorders’ (Visser and van Dieen, 2006). In this study, all these terms are used interchangeably with RSI.

**Table 3.1. List of terms used (almost) synonymously with repetitive strain injury**

<b>Country/region</b>	<b>Acronym</b>	<b>Synonym/ term used</b>
UK, Canada, Netherlands	RSI WRULD or ULD	Repetitive strain injury and work related upper limb disorders or upper limb disorders
USA	CTD UECTD RMD	Cumulative Trauma Disorder/ Upper Extremity Cumulative Trauma Disorder (UECTD), and Repetitive Motion Disorder
Australia/New Zealand	OOS OOI	Occupational Overuse Syndrome (OOS), and Occupational Overuse Injury (OOI)
Japan, Scandinavia Germany	OCD	Occupational Cervicobrachial Disorder (OCD)

Scandinavia, Switzerland, Sweden		Tension neck
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It is interesting to note that in the USA, the synonymous term cumulative trauma disorder (CTD) is used by the government to describe ‘any musculoskeletal pain that an individual thinks is associated with activities performed at work’ (Melhorn, 1998). The term is used to apply to conditions where it is the individual who is making the work–pain association.

### **3.3.1 Controversy over the terminology**

The RSI term has been considered to be ‘inappropriate’ and ‘misleading’ because it implied that repetition and injury were involved (Gun and Jezukaitis, 1999: 83). Macfarlane et al, (2000) also stated the term RSI should be avoided because it implied a single uniform aetiology, which was not the case. Hagberg, (1996) stated the term RSI was criticised because it suggested a pathological mechanism for which there was usually no evidence, it encompassed disorders such as carpal tunnel syndrome and de Quervain’s disease which were not necessarily related to repetitive tasks or cumulative trauma, and ignored the role of psychological and social factors in the onset and persistence of work related musculoskeletal disorders. Others have argued that repetitive movements are not the only cause of RSI, since extended periods of immobility can lead to static contractions and result in the condition (Melhorn, 1998). Cohen, (2004) stated the term RSI suffered from a failure of denotation since it was unclear to which clinical conditions the name should be applied and the name incorporated a hypothesis of causation.

Two years after the term ‘RSI’ was introduced, The Australian Medical Council tried to have the name officially changed to ‘Regional Pain Syndrome’ because the term RSI was considered to be too emotive and because it focused on injury (Littlejohn, 1995; Helliwell, 1996). Authors such as Littlejohn, (1995) and Melhorn, (1998) have argued that there is no ongoing injury in RSI, but that some dysfunction to the sensory pathways may have resulted in changes in pain perception. Littlejohn, (1995) stated there were medico-legal repercussions in implying that injury had



occurred, and may encourage people to seek a cure for their injury, or ‘proof’ of their injury from the medical profession as evidence in legal compensation action.

### **3.3.2 Global terms used synonymously with RSI**

Despite concerns that the term RSI is inappropriate or unhelpful, it has become generally accepted and is notionally understood by the public in the UK, Netherlands and Canada. Other terms used synonymously or interchangeably with RSI are listed in Table 3.1 (compiled from Arskey, 1998; Tyrer, 1999; Lynn, 2006; Melhorn, 1998; Blatter et al, 2004; Hutson, 1999).

### **3.3.3 Diagnosable and non-diagnosable forms of RSI**

The broad term ‘RSI’ covers a range of disorders. Whilst many of these disorders have a clinically defined pathology and can usually be diagnosed, others have an ill-defined aetiology, are difficult to diagnose and remain a source of medical and legal controversy (Winspur, 2001). Knowledge of RSI varies depending on the particular discrete condition concerned. For example, carpal tunnel syndrome (CTS) is more readily explained since it demonstrates visible pathological change and can be directly measured using diagnostic tests (Pheasant, 1992). These two factors together with the use of mathematical modelling have provided a reasonably clear picture of the pathology of the condition (Buckle and Devereux, 1999). Some health professionals, however, have questioned the utility of classifying together such a heterogeneous group of conditions, some of which are well understood and others not. For example, Tyrer, (1999) advocated conditions currently grouped under the RSI rubric would be better served separated into those with ‘a clearly demonstrable pathology such as carpal tunnel syndrome’ and those with ‘ill-defined symptom complexes with diffuse aching, weakness and muscle tenderness’. Reiterating Hutson’s (1999) idea, Tyrer, (1999) referred to these two groups as ‘Type 1’ and ‘Type 2’ WRULDs (see Table 3.2.)

### 3.3.3.1 Type 1 WRULDs

According to Tyrer (1999) and Hutson (1999), Type 1 WRULDs such as carpal tunnel syndrome and others listed below have distinct visible pathology which can be demonstrated using diagnostic tools, such as nerve conduction tests, radiography, ultrasound scans, magnetic resonance imaging (MRI) or surgical procedures. In other words these conditions conform to 'disease' in the classic disease-illness model, have clinical signs that are reliably reproducible and have standard treatments (Hutson, 1999). A list of Type 1 WRULDs is provided in Table 3.2.

**Table 3.2: List of discrete diagnosable Type 1 WRULDs conditions (from Tyrer, 1999)**

- De Quervain's tenovaginitis;
- Supraspinatus tendonitis;
- Peritendinitis crepitans;
- Carpal tunnel syndrome;
- Cubital tunnel syndrome (entrapment of the ulnar nerve at the elbow);
- Lateral epicondylitis (tennis elbow);
- Medial epicondylitis (golfer's elbow);
- Rotator cuff syndrome;
- Dupuytren's contracture.

However, in a similar list compiled by Helliwell and Taylor, (2004) these authors also added pronator syndrome, ulnar tunnel syndrome, radial tunnel syndrome, thoracic outlet syndrome, cervical radiculopathy, tenosynovitis, bicipetal tendonitis, frozen shoulder as other recognised arm disorders. They also included arthritis.

### 3.3.3.2 Type 2 WRULDs or non-specific diffuse RSI

In contrast, Type 2 WRULD refers to the diffuse form of upper limb disorders and is a regional pain syndrome of which our understanding is more limited. The symptoms usually relate to muscles or nerves; typical muscle symptoms include pain, aching,

tiredness, cramp, weakness, tremor, and loss of function such as grip (Helliwell, 1996). The nerve related symptoms in non-specific diffuse RSI include numbness, paraesthesiae (pins and needles), allodynia (reduced thresholds), hyperalgesia (increased response to afferent input) subjective swelling, burning and lack of coordination (Helliwell, 1996; Cherniack, 1996; Konijnenberg et al, 2001; Hutson, 1999). However, Cohen, (2004) pointed out that the fundamental clinical problem with these diffuse forms of upper limb disorders was the presence of persistent pain in the absence of discernible disease or injury, which challenged Western medicine. This has led to a wide spectrum of views regarding the status of non-specific forearm pain – from acceptance to dismissal (Winspur, 2001; Harrington et al, 1998). Although this debate remains unresolved, Cohen (2004) argued that these polarised medical views had at least encouraged debate and the need to look beyond the traditional biomedical model for medical solutions.

Whilst the aetiology of type 2 WRULDs continues to be debated, some clinicians attribute Type 2 WRULDs to an organic pathology believing there is some initial form of mechanical injury or trigger where ‘micro traumas’ over long periods result in damage to soft tissue, which then leads to localised inflammation. Normally this damage would heal, but, if rest breaks are insufficient for natural healing to occur, then pain and discomfort may follow and result in disability (Blatter et al, 2004; Visser and van Dieen, 2006). Other authors argue that the cause of type 2 RSI is likely to be neural dysfunction in the pathways responsible for pain perceptions and other sensations.

In an effort to address the lack of agreement on diagnostic criteria for RSI, Harrington et al, (1998) attempted to develop consensus case definitions for nine upper limb conditions including non-specific forearm pain. A core multi-disciplinary group of 29 experts involved in RSI clinical management or epidemiological investigations, participated in a postal Delphi exercise. The nine specific RSI conditions selected were CTS, tenosynovitis (wrist), pain syndrome in forearm or hand, lateral epicondylitis, frozen shoulder, De Quervain's tenosynovitis, shoulder tendonitis, shoulder capsulitis and thoracic outlet syndrome. The group reached consensus on eight conditions, but felt they lacked relevant expertise to define thoracic outlet syndrome.

Whilst participants held differing opinions on whether and how non-specific diffuse forearm pain should be characterised, on balance the core group agreed that diffuse forearm pain probably was a real clinical entity, but considered the term 'RSI' unhelpful. The consensus definition reached for non-specific diffuse pain was 'pain in the forearm in the absence of a specific diagnosis or pathology'. A common view was that the diagnosis of non-specific forearm pain was made by exclusion, which influenced the way criteria were framed. Whilst it was recognised that features such as loss of function, weakness, cramp, muscle tenderness, allodynia, and slowing of fine movements may be present, these were not considered to be specific defining criteria. These consensus definitions, however, do allow comparisons to be made between research studies and may help RSI case management and surveillance programmes. The lack of diagnostic tools to detect the non-specific diffuse RSI make its existence difficult to prove, creating difficulty for both individuals and health professionals (Barker, 1995).

According to Sheon, (1997), diagnosis of RSI is subjective because most tests have low specificity. A clinical diagnosis is usually reached by assessing local tenderness combined with a history of appropriate symptoms. Katz et al, (2000) stated that no standard criterion were available for any of the upper extremity soft tissue musculoskeletal disorders and that in his experience diagnosis was reached on the basis of clinical impression, individual history, physical examination and laboratory evaluation (Katz et al, 2000).

Given these difficulties in diagnosing RSI, the HSE commissioned research to develop an efficient way of standardising the diagnosis and assessment of upper limb disorders. This involved the development and piloting of a computerised decision support system which used a simple flow diagram to lead users (general practitioners, GP, or occupational physician, OP) through options based on the presence or absence of standard criteria. Initial testing of the system involved using actors trained to present with typical RSI symptoms. The second stage involved the practical application of the system during normal consultations with patients for eight weeks in which 285 GP and 264 OP consultations took place. Results of this study suggested the system was effective in increasing the number of correct diagnoses made compared to conventional diagnostic approaches, produced fewer incorrect diagnoses, and was helpful in diagnosing non-specific problems and undecided diagnoses (Graves et al, 2000). Whilst the results were statistically significant, the

sample size was relatively small in field trials (only 33 OP and 33 GPs took part) but the system showed considerable promise.

### **3.4 Risk Factors for RSI**

The development of upper limb disorders has attracted much interest and debate. Their aetiology is complex, arising from the interaction of physical, psychosocial and personal factors. Risk factors are factors which affect the development of RSI whilst prognostic factors are factors which affect the progress of RSI in those who already have RSI symptoms (Blatter et al, 2004). Theories to explain forearm pain range from exposure to mechanical factors such as frequent repetitive movements of the upper limb, to the pain being considered as a regional form of a fibromyalgia-type syndrome associated with high levels of psychological distress and somatisation (Blatter et al, 2004; Hutson, 1999; Macfarlane et al, 2000). Whilst the role of mechanical factors such as repetitive movements have long been implicated in the onset of forearm pain (Gerr et al, 1991; Melhorn, 1998; Hutson, 1999; Buckle and Devereux, 1999), Macfarlane et al, (2000) found that forearm pain onset was not exclusively due to mechanical factors but was independently related to psychological factors, illness behaviour, other somatic symptoms, and work-related mechanical and psychosocial factors (Macfarlane et al, 2000).

#### **3.4.1 Physical risk factors**

##### *3.4.1.1 Historical perspective*

Contrary to commonly held beliefs, RSI is not a *new* condition but rather an old one in new guise. This is the conclusion of Quintner, (1991), based on a historical literature review of work-related upper limb disorders to examine whether RSI was a new medical phenomena or a pre-existing one. According to Quintner, (1991), several similar outbreaks of pain linked to the evolution of work practices could be identified over the past 150 years or so. Examples included the increased prevalence of 'writers cramp' when steel nibs replaced the quill pen, and again when

biros were introduced (Melhorn, 1998; Tyrer, 1999). Moreover pain symptoms of scribes and notaries reported by Ramazzini overlapped neatly with the range of conditions now termed 'RSI'. Furthermore, Ramazzini attributed the pain at that time to the use of quill pens, poor seating and excessive mental labour (Ramazzini, 1713 in Wright, 1964). These risk factors appear similar to those being currently suggested to explain RSI such as ergonomic factors, equipment/tools, posture and psychosocial stress.

#### *3.4.1.2 Current understanding of physical risk factors*

There is now sufficient evidence to support the view that repetitive work involving frequent movements (regardless of force used) increases the risk of RSI conditions and symptoms (National Research Council and the Institute of Medicine, 2003 in Blatter et al, 2004). This finding is based on studies in which strain at work was measured rather than on information collected from surveys (Blatter et al, 2004). It is now believed that in addition to repetitive movements, the use of excessive force or adopting awkward postures whilst carrying out repetitive movements can also result in tissue damage and pain (Gerr et al, 1991; Hutson, 1999; Buckle and Devereux, 2002). Small repetitive movements, or micro traumas, that accumulate over long periods, can result in minute tears to the muscle fibres thus damaging them (Blatter et al, 2004). Other risk factors leading to RSI symptoms are thought to be compression of the median nerve resulting in changes to the sheath around the nerve. Whilst several models have attempted to conceptualise and predict the cause and development of work-related MSDs, none can adequately explain its development (Melhorn, 1998). Some of these models are discussed next. There is some evidence to support links between computer use and RSI symptoms with risk linked to the number of hours a day spent doing such work. Incorrect neck and wrist positions are also believed to be important risk factors. For example, Marcus et al, (2002) found that the risk of symptoms more than doubled in those using computers for more than 35 hours a week compared to those using them for 15 hours a week. Whilst there is still insufficient research, frequent arm movements, particularly if force is involved, considerably increases the risk of RSI. For people using computers this risk increases when computer work is carried out for extended periods. A large scale study involving 8,000 workers found the main physical risk

factors for upper limb disorders were awkward posture, remaining seated for 30 minutes for more without a break, vibration, repetitive wrist or arm movements and using a keyboard more than 4 hours a day (Devereux et al, 2004).

### **3.4.2 Psychosocial and psychological risk factors**

Mounting evidence now suggests that psychosocial factors in the workplace contribute significantly towards the development and maintenance of occupational disorders such as RSI and back pain (Vlaeyen and Linton, 2000; Blatter et al, 2004; Devereux et al, 2004). Psychosocial factors cover many aspects of the work environment, both physical and psychological (Buckle and Devereux, 2002). Examples include personal relationships between the employee, manager and work colleagues and the physical work environment (Buckle and Devereux, 2002). A HSE funded prospective epidemiological study involving 8,000 workers from 20 organisations was conducted to establish the role of stress and psychological factors in musculoskeletal complaints (Devereux et al, 2004). The sample comprised 70% white collar workers and 30% blue collar workers. For hand/arm/neck/shoulder complaints, key psychosocial risk factors were intrinsic effort (worker's inability to cope with demands, inability to relax after work etc), role ambiguity and conflict, low reward, future uncertainty over job and threat of harm or injury (Devereux et al, 2004). Stress was seen as an important mediator in the reporting of complaints. Helliwell and Taylor (2004) found employees' perceptions regarding their level of control over their work, job motivation and satisfaction, and whether the work is considered monotonous or interesting and variable could all influence the onset of upper limb disorders.

It is generally recognised that work related pressure and stress are important risk factors in RSI (Hutson, 1999; Cohen, 2004; Blatter et al, 2004; Devereux et al, 2004). Macfarlane et al, (2000) examined the relationship between stress and RSI and concluded that there was a link between them with stress being more important than the degree of control over work or support from colleagues. Blatter et al, (2004) found that a high workload that exceeded an individual's capabilities and caused them stress was also an important factor in contributing to the onset of RSI.

A prospective cohort study by van den Heuvel et al, (2005) involving 1029 blue and white collar workers from 34 companies investigated the relationship between psychosocial work characteristics and neck, shoulder, elbow, hand and wrist symptoms. This study concluded that severe work pressure that placed high demands on the individual doubled the risk for both neck/shoulder symptoms and elbow/wrist/hand symptoms. Low social support was found to be a risk factor for elbow/wrist/hand symptoms but not for neck/shoulder symptoms. These relationships were mediated by an increased exposure to physical risk factors and stress (van den Heuvel et al, 2005). However, there are inherent methodological difficulties with trying to find empirical evidence for RSI aetiology, work causation or symptom onset, because of the high number of factors involved which must be controlled and because of the difficulty in accounting for the effect of personal factors such as negative affects, different coping styles, different individual reactivity to exposure and people changing their jobs. The literature indicates that this is still a developing area of research and the complexity lies in studying all the variables independently to establish their effect. However, it is evident that psychosocial factors are highly important, particularly perceived stress. They also support the potential utility of the biosychosocial model in managing such disorders.

### **3.5 Models to explain RSI aetiology**

In an early attempt to explain the aetiology of RSI, Armstrong et al, (1993) proposed a model based on four sets of interacting variables: exposure, dose, response and capacity which were believed to determine the risk of injury. In this model, *exposure* referred to physical and psychosocial factors; *dose* referred to mechanical forces on body tissues, changed levels of metabolic substrates such as muscle glycogen and psychological disturbances; *response* referred to the body's response to changes in muscle tissue shape and composition, cell membrane permeability changes (which could result in toxin accumulation in muscle tissue) and increased muscle tension, possibly due to stress. The fourth variable in the model, *capacity*, is an individual's resistance to these changes. This basic model still provides a basis for explaining RSI development. More recently, Devereux et al, (2004) stated high mental workload and job demands may increase muscle tension, and decrease micro pauses in muscle activity resulting in muscle fatigue. In addition, mental overload



and high job demands may produce an adverse immune system response. Stress may also cause behavioural changes such as not taking rest breaks or adopting poor work practices to get work done quickly which increase the loading on the musculoskeletal system (Devereux et al, 2004).

### **3.6 RSI: the legal debate**

RSI has long been the subject of medical debate and legal wrangling (Boyling, 1998; Winspur, 2001). This section considers only the litigation argument – i.e. whether the courts agree about ‘RSI’ – rather than the statutory duties under the health and safety at work act and its regulations. The legal picture of RSI remains confusing. Although there was a rise in legal claims in the UK through the 1990s (Boyling, 1998), since then, there have been comparatively few cases involving white collar workers, following a number of unsuccessful cases (Winspur, 2001). However there have been some blue collar cases involving poultry processing companies e.g.: *Franklyn v Sun Valley Poultry*; *Montenay and others v Bernard Matthews*. However, these cases involved people with tenosynovitis which is clinically easier to prove. From a legal standpoint, the most important cases are those that go to the Court of Appeal or House of Lords since that is where they can set a precedent.

Notable legal cases involving RSI include that of *Mughal v Reuters*, in which High Court Judge Prosser commented that RSI was ‘meaningless’ and had no place in the medical textbooks [*Mughal v Reuters*, 1993]. Such cases have highlighted the complex nature of the complaint and difficulties in explaining the cause/effect relationship in alleged work-related disorders (Barker, 1995).

One landmark case in RSI is *Pickford v. Imperial Chemical Industries Plc* [1998] UKHL 25 which went to the House of Lords. Although the House of Lords eventually decided against Mrs Pickford, it nonetheless acknowledged that RSI did exist. Although *Pickford* failed, it led to several successful claims by employees, notably in *Alexander and others v Midland Bank* [1999]. This case involved a number of people employed purely to encode data from cheques using key depression rates averaging 12,700 per hour.

A third important case point is that the earlier comment made by Judge Prosser in *Mughal v Reuters* that RSI was 'meaningless', was subsequently countered in the *Alexander* judgement in which the judge said:

"Simply because the precise pathological/physiological explanation could not be explained by the existing techniques, does not mean that these conditions were all in the mind".

More recently in *Amanda Chinn v Cyclacel Limited*, [2007], Chinn sought damages for RSI she alleged was acquired from her work using pipette guns in a laboratory for several hours over a period of months and sometimes in awkward positions. However in this case the judge ruled that a claim based on RSI was not a relevant claim. The literature indicates that the legal aspects of RSI remain confusing and unresolved. However, successful RSI cases are rare due to the two key issues of proving its existence and that it was caused by work.

### **3.7 A confusing picture of RSI**

Our knowledge of RSI is far from complete. In reviewing selected literature on RSI, it can be seen that a confusing picture emerges with many controversies and inconsistencies both medical and legal. Intense debate remains about usage of the term 'RSI', its precise meaning and resistance to its medicalisation persists, placing it in the group of medically contested illnesses alongside FM, CFS and non specific low back pain. Furthermore, no standard definitions for RSI exist with different countries using different systems which make establishing a coherent global picture difficult. At the heart of the RSI problem lie two key issues; diffuse RSI symptoms lack visible pathology which challenges Western medicine (Cohen, 2004) and central to the medical and legal debate is whether RSI is work – related. Whilst many studies have shown relationships and evidence of associations between factors in the workplace and RSI type conditions, none has been able to prove this conclusively. Methodological difficulties of such studies include controlling for variables such as people's different coping styles, differences in how they react to exposure to risks and sample size. Furthermore, Arskey, (1998) stated that the

medical status of RSI provided an arena for professional rivalry between different medical specialities.

To address many of these issues, a report by Burton et al, (2008) suggests a cultural shift is needed in the way that musculoskeletal disorders such as RSI are viewed in the workplace if they are to be successfully managed. Burton et al, (2008) discouraged the use of the term 'work- related', replacing it with the term 'work-relevant' to remove the automatic association made with work, since it is argued that such disorders are common both in and out of the workplace.

### **3.8 Summary of our current understanding of RSI**

This chapter highlighted that work-related upper limb disorders represent a significant health problem in the work place which is little understood. RSI is not new, as outbreaks linked to the evolution of work practices have been found for at least the past 150 years. There is mounting evidence that psychosocial factors in the workplace contribute significantly to the development and maintenance of RSI. However, despite its growing significance and increasing research, many controversies still surround RSI. It lacks a standard definition, its medical construction is still evolving, the extent to which RSI is work-related is still debated, and it has an uncertain medical and legal status. The term RSI encompasses both disorders that can be diagnosed and those that cannot. Approximately 50% of all RSI cases have no clinical signs or pathology and are referred to as non-specific diffuse forearm pain (Lynn, 2006). No universally accepted theory exists to explain the physiological mechanisms for RSI, but Visser and van Dieen (2006) have found promising theories to be damage to muscle cells or restrictions in blood circulation. Few legal actions in the UK concerning employer negligence over RSI have been successful due the difficulty of proving the existence of RSI and that it is caused by work. The use of the RSI term is opposed because it is considered emotive, implies causation and potentially has legal connotations. Despite this, the use of the term RSI has continued (Arskey, 1998; Lynn, 2006). The term RSI is used in this study since this is the term used by the lay participants involved in this study and the national association representing their interests.

Having discussed the complex background to RSI, the next chapter considers how RSI type conditions are managed. This is necessary to understand since how it is managed affects the individual's experience of having RSI.

## **4 Chapter 4: RSI Disability, Management and Rehabilitation**

### **4.1 Introduction**

As discussed in Chapter 2, pain is a primary presenting symptom in RSI (Pilgion et al, 2000). Whilst in many cases this pain eventually dissipates, in some cases it can persist and become chronic pain. Such pain is disabling and can result in job loss, social isolation and a collapse in family relationships (Pilgion et al, 2000). Whilst it is believed that minor injury may initially cause RSI, psychosocial factors discussed earlier in Chapter 2 (such as pain beliefs, fear avoidance behaviour and coping strategies) may subsequently maintain it (Helliwell and Taylor, 2004; Hutson, 1999). The clinical management of RSI must therefore address the pain symptoms per se, the consequent disability and the underlying psychosocial factors which maintain this pain and disability. The aim of this chapter therefore is to provide an overview of how chronic pain arising from RSI is currently managed at the clinical, occupational and personal level and its rehabilitation.

Since disability resulting from pain plays a key role in RSI (and other chronic pain conditions) it is useful to begin by considering what we mean by disability.

### **4.2 Definitions of disability**

#### **4.2.1 Social science approaches to disability**

Disability is a complex socially constructed term encompassing meaning at both societal and individual level. It has been viewed in different ways including a 'personal tragedy', to a form of social deviance (Parsons' sick role, discussed in

Chapter 5), a type of social oppression and in terms of impairment and the body (Barnes and Mercer, 2003). It is this latter meaning of disability which is most relevant to this study of RSI experience. From an individual's perspective, disability interferes with their ability to perform a task or activity due to some disruption to the individual's physical or mental functioning (WHO, 2001). The disabling consequences of persistent pain can lead to reduced physical functioning and may restrict many aspects of people's daily living (Main et al, 2000 in Main and Spanswick, 2000). It is important therefore to consider how such pain related disabilities arise, as these interfere with desired functioning and must be managed. The following models have attempted to explain disability.

### 4.3 Models of disability

#### 4.3.1 The WHO biopsychosocial model of disability

The WHO has produced a revised International Classification of Functioning, Disability and Health, known as the ICF to enable health and related states to be described using a common language across the world (WHO, 2001). This ICF system replaces the 1980 International Classification of Impairments, Disabilities and Handicaps (ICIDH). The ICF has two parts; Part 1 covers Functioning and Disability with Body Functions and Activities and Participation and Part 2 covers contextual factors including environmental factors and personal factors (WHO 2001). The ICF differs to its predecessor in its interpretation of 'health' and 'disability' which are now based on a biopsychosocial model which extends the concept of disability from purely 'medical' or 'biological' dysfunction to one encompassing the social aspects of disability (Taylor and Bury, 2007). Within ICF, disability is considered to result from the interaction between an individual with poor health and their personal and environmental factors (WHO, 2001). Environmental factors are those "which make up the physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2001:171). The ICF defines disability in terms of functioning in different areas of life such as employment, mobility or accessing health services. This model represents a shift in emphasis from causes of health and illness to their consequences for the individual (WHO, 2001).

Various other models have also been proposed to explain the disability arising from chronic pain and are considered next.

## **4.4 Chronic pain models of disability**

Research interest in the relationship between pain and disability emerged from efforts to understand the multi-factorial aetiology, nature and consequences of chronic pain (Main et al, 2000 in Main and Spanswick, 2000). Current research suggests that people's behaviours and beliefs about pain and injury or harm are important determinants of the level of pain disability experienced by individuals (Turk and Okifuji, 2002; Vlaeyen and Linton, 2000; Vlaeyen and Crombez, 2007). Therefore unravelling the complex relationship between pain, impairment and disability is the key to understanding musculoskeletal pain and disability and to improving its management. The fear avoidance model discussed in Chapter 2 has helped to explain the relationship between pain and disability. However, several other models have also attempted to explain the relationship between behaviour and level of pain disability experienced and are discussed next as background to pain and disability in RSI.

### **4.4.1 The Emory Pain Estimate Model**

The Emory Pain Estimate Model, proposed by Brena and Koch, (1975 in Main and Spanswick, 2000), was an early attempt to understand the relationship between pain disability and behaviour by investigating pathology (diagnosis and physical examination) and behaviour (pain reports, activity scales, medication use etc.). However this model was methodologically flawed and was superseded by subsequent models (Main and Spanswick, 2000).

### **4.4.2 The Glasgow Illness Model**

The Glasgow Illness Model proposed by Waddell et al, (1984 in Main and Spanswick, 2000) attempted to understand why some patients became more

disabled than others despite comparable levels of physical impairment. This research suggested that in non-specific low back pain patients, the extent of disability experienced correlated more closely with distress and pain behaviour than to impairment. However this study failed to fully consider several important factors such as social and occupational variables, pain beliefs, fear or coping strategies (Main and Spanswick, 2000).

#### **4.4.3 The Multiaxial Assessment of Pain**

Turk and Rudy (1992) attempted to understand pain disability from a bio psychosocial perspective by integrating biomedical, psychosocial and behavioural data. Using a classification system for chronic pain patients called the Multiaxial Assessment of Pain (MAP), they identified three personality types based on people's response to pain, their beliefs and the level of disability experienced. These were: the 'Dysfunctional personality' (high perceived pain severity and interference, with high levels of distress and low activity), the 'Interpersonally distressed' (who perceived others to be unsupportive) and 'Adaptive copers' (those with high levels of social support, low levels of pain, interference and distress and higher activity and more perceived control). Whilst this model was a useful screening tool showing that similar kinds of patient could develop quite different pain problems, it was considered inadequate for the assessment of individual patients (Main et al, 2000 in Main and Spanswick, 2000).

Subsequently, research focused on the role of psychological factors as mediators in pain and disability since these were considered more predictive of disability than biomedical or ergonomic factors (Main et al, 2000). Efforts were made to understand how people's beliefs about pain, its controllability, the influence of fear, anxiety, people's expectations of treatment outcomes and coping strategies affected pain and disability (Main et al, 2000).



#### **4.4.4 Gatchel's Three Stage Model**

A three stage model was developed by Gatchel (1991 in Main and Spanswick, 2000) proposed to explain the development of chronic pain disability in chronic low back pain patients. The first stage was characterised by emotional distress due to fear, anxiety and worry about the pain. If the pain persisted for more than 2-4 months, psychological and behavioural disorders such as depression and anger may develop. If the pain still remained unresolved, the patient entered the third chronic pain stage. Mayer and Gatchel, (1998) later expanded the model to include physical deconditioning, which referred to the loss of muscle strength, flexibility and endurance. Whilst this model conceptually advanced understanding, it did not adequately explain the development of chronicity.

#### **4.4.5 Melzack's Neuromatrix Theory (Melzack, 1999)**

Some features of this model were discussed earlier in Chapter 2 where it was noted that stress could be a mediating factor in pain perception. Melzack's (1999) neuromatrix theory uses homeostatic principles to explain the development of chronic pain disability mediated by the stress regulation system. The theory relates the emotional impact of chronic pain to the stress which accompanies pain and these two systems are known to share similar mechanisms (Main et al, 2000 in Main and Spanswick, 2000). It posits that injury disrupts the body's normal homeostatic system and induces stress. The body attempts to restore this balance through activating neural, hormonal and behavioural activity. If the stress regulation system remains activated for long periods, this can suppress the immune system and activate the limbic system which is important in emotion, motivation and cognitive processes (Main et al, 2000 in Main and Spanswick, 2000). This change can in turn lead to the development of fibromyalgia and other chronic pain conditions (Main et al, 2000 in Main and Spanswick, 2000). It explains disability as attempts by the individual to manage stress and restore equilibrium by minimising or avoiding pain. The avoidance of activity and fear of pain in attempts to escape from it may help explain the development of the 'disuse syndrome' (Main et al, 2000 in Main and Spanswick, 2000).

#### **4.4.6 Main *et al*'s seven stage model of pain disability**

Factors considered in previous models of disability were extended by Main *et al*, (2000) by taking into account biomedical, physiological, psychological, socioeconomic and iatrogenic factors. Their model suggested pain disability arose from the avoidance of activity which led to physical deconditioning which in turn resulted in more inactivity and disability. If pain persisted, then emotions such as anger, frustration and depression became more important. These could lead to cognitive distortion and catastrophising which could exacerbate pain and disability and develop a 'learned helplessness' (Main *et al*, 2000 in Main and Spanswick, 2000). Ineffective treatments, clinicians' disbelief about pain or attributing pain to psychological causes could all compound patient anger and frustration. The role played by family in the development of disability is considered important and family involvement in pain management programmes is encouraged. The influence of wider socioeconomic and occupational factors on pain and response to treatment are also considered. Given the complexity of pain and disability in chronic pain conditions, Main *et al*, (2000) suggested that such conditions were better understood within a biopsychosocial framework which addressed a broad range of factors in addition to impairment. However, the challenge in managing pain and disability is to understand how these multiple factors interact to influence the individual patient being treated (Main *et al*, 2000 in Main and Spanswick, 2000).

The next section looks at some of the difficulties faced by clinicians in the clinical management of RSI pain, how it is currently managed and its effectiveness.

### **4.5 The Clinical Management of RSI pain**

#### **4.5.1 Background issues impeding management of RSI**

RSI is a common health and occupational problem with a UK population prevalence rate of 10-15% (O'Neil *et al*, 2001; van Tulder *et al*, 2007; Helliwell and Taylor, 2004). Despite being a significant problem, both empirical and practical evidence suggest that its clinical management is poor (Cohen, 2004; MacIver *et al*, 2007; van Tulder *et al*, 2007). This is generally attributed to its complex nature (Feuerstein *et*

al, 1993). However, more specific explanations for its poor management relate to two key aspects of the RSI debate: the link between RSI and work and the acceptance of diffuse non specific RSI as a genuine medical condition.

#### *4.5.1.1 Link between work and RSI*

RSI occupies an unusual position in both traditional and occupational medicine (Cherniack and Warren, 1999). As an occupational injury it is challenged on two grounds; because of a lack of conclusive evidence of a direct causal relationship between work and RSI and because it can arise from avocational activities and leisure pursuits (Hadler, 2003; Melhorn, 1998; Cohen, 2004). Furthermore, methodological limitations make establishing the causal relationship between work and RSI problematic because of the difficulty in disentangling the cognitive and physical aspects of a task, controlling for the effect of risk factors both within and outside the workplace and different relative exposure levels and also because of what we mean by the state of 'well being' given its cognitive, emotional and physical basis (Cherniack and Warren, 1999).

#### *4.5.1.2 Medical acceptance of non-specific diffuse RSI*

A second major issue in RSI management concerns the medical acceptance of non specific diffuse arm pain as a genuine clinical condition (Arskey, 1998; Spence et al, 2001). Such cases comprise at least 50% of RSI cases (Lynn, 2006) with other authors estimating a much higher figure (Sluiter et al, 2001). It is argued that non specific diffuse RSI patients who present with symptoms of illness without discernible signs of disease or injury, challenge clinicians' traditional notion of disease (Willis, 1986; Cohen, 2004; Lynn, 2006). Some clinicians attribute RSI to psychological causes in the absence of visible pathology (Page and Wessely, 2003; Asbring and Narvanen, 2003). As discussed earlier in the thesis there remains considerable resistance to the medicalisation of RSI behind which, Arskey, (1998) argues, lies professional rivalry and power struggles.

Other factors which make RSI management challenging are its uncertain aetiology since the presenting pain symptoms may originate from nerve impingement, vascular problems or degeneration of the cervical spine and is complicated further if several lesions are contributing to the pain (Sola, 2003).

As discussed in Chapter 3 the term 'RSI' is problematic because its implied causation has implications for its management. It has been argued that RSI is not a diagnosis, but rather a statement of causation (Konijnenberg et al, 2001; Bird, 2005). The term 'RSI' is considered inappropriate, emotive and said to carry implications of employer liability in the word 'injury' which could lead to patients pursuing a legal claim against their employer. In efforts to remove this element of causation in the term 'RSI', the National Occupational Safety and Health Service in New Zealand replaced RSI with the term Occupational Overuse Syndrome (OOS). This body argued that all three words in the title 'Repetitive Strain Injury' were misleading since the main cause was muscle tension, not repetition; the word 'strain' was not a strain in the normal sense of the word, and the word 'injury' was misleading because the condition was usually reversible (OOS Treatment and Rehabilitation, 1997). However despite this and other attempts to replace RSI with other terms such as work related upper limb disorders and local regional pain syndrome (Bird, 2005; Littlejohn, 1995), the term RSI has become entrenched in common usage. Burton et al, (2008) have also suggested moving away from using the term 'work-related' when referring to such disorders.

#### *4.5.1.3 Treatment of RSI*

Currently there are no evidence based guidelines for the treatment of non specific arm pain. Furthermore, those treatments which are used have been described as "unfocused and unsatisfactory" (MacIver et al, 2007) or deemed largely ineffective (Cohen, 2004; van Tulder et al, 2007). Piligian, (2000) stated common RSI symptoms which needed to be clinically managed were pain aggravated by activity, tenderness, swelling, numbness, stiffness, loss of grip and dexterity and cold intolerance. Standard treatment approaches used for the clinical management of non specific diffuse RSI are narrower and include analgesia, physiotherapy, ergonomic modifications and paying attention to psychological factors (MacIver et al, 2007). Standard treatments used for RSI in general are rest, workplace changes, anti-inflammatory or pain medication, wrist splints, physical therapy, cortisone injections, compression straps, acupuncture or surgery (Piligian et al, 2000).

## **4.6 Evidence for effectiveness of RSI treatment**

Despite the long list of treatments used to treat RSI, little strong empirical evidence exists to support their use. For example Konijnenberg et al, (2001) conducted a systematic review to evaluate the effectiveness of different treatments in relieving RSI symptoms and improving activities of daily living. Interventions reviewed included occupational therapy, physiotherapy, multidisciplinary treatment, medication or ergonomic modifications (such as to computer keyboard and mouse). These authors found no strong evidence overall for the effectiveness of any treatment options, but cautioned that this did not mean that the treatments had no effect. Limited evidence was however found for multidisciplinary rehabilitation, ergonomic interventions, exercise, therapy and spinal manipulation in providing symptom relief, or improving activities of daily living. They found evidence relating to the effectiveness of behavioural therapy was conflicting. Konijnenberg et al, (2001) concluded that currently the picture was unclear about the effectiveness of conservative treatment for RSI.

In a more recent narrative review, van Tulder et al, (2007) reiterated earlier findings that whilst a range of treatments were used in daily practice to manage patients with specific and non specific RSI, there was no convincing evidence for their efficacy and any pain relief obtained appeared to be short term. Van Tulder et al, (2007) concluded that the use of RSI treatment was therefore pragmatic rather than evidence-based, although the use of such treatments may be supported by long standing practice. Common treatments reviewed were rest, medication, exercise therapy, physical therapy, behavioural therapy, occupational therapy, ergonomic interventions or a combination of these treatments. Some evidence was found for the effectiveness of exercise therapy for symptom relief and improved activities of daily living for non specific diffuse RSI (van Tulder et al, 2007).

Crawford and Laiou, (2007) were commissioned by the HSE, to review current evidence for the clinical management of both specific and non specific upper limb disorders, to determine best treatment practice. As part of this exercise, Crawford and Laiou also reviewed pain management programmes for the treatment of upper limb disorders. They found only limited evidence of their efficacy based on three studies (Johansson et al, 1999; Marhold et al, 2001; Karjanainen et al, 2000) which

gave conflicting results because of the different treatments and outcome measures used.

These reviews suggest that despite widespread use of interventions to manage RSI, strong empirical evidence to support and guide clinicians responsible for managing RSI patients was lacking. This may contribute to its poor management.

## **4.7 Rehabilitation programmes**

The literature on the effectiveness of rehabilitation programs is conflicting. For example, in a systematic review to determine the effectiveness of biopsychosocial rehabilitation of RSI, only weak scientific evidence for the effectiveness of biopsychosocial rehabilitation for RSI was found (Karjanainen et al, 2000). Lindh et al, (1997) conducted a randomised controlled study for rehabilitation of individuals with non specific musculoskeletal pain consisting of 158 patients and a control group of 226 and found no significant difference in treatments. In contrast, Feuerstein et al, (1993) found a greater success in return to work in limb pain patients attending a rehabilitation programme comprising physical conditioning, work conditioning, pain and stress management, ergonomic consultation, and vocational counselling/placement when compared to usual care (74% compared to 40%). However, it is difficult to identify which components were of particular benefit in this study and the inherent limitations of being a small scale study (n=34).

Some of the methodological issues encountered in these studies were that only RCTs are included so whilst many other studies may exist, they are excluded and RCTs may be difficult for e.g. physiotherapy. In addition, subjects often cannot be fully blinded as they can in drug trials as the individual will be aware of which treatment they are receiving. Furthermore, studies tend to be small scale, of poor methodological quality, use different controls and multiple outcome measures (Morley et al 1999; Crawford and Laiou, 2007; van Tulder et al 2007; Konijnenberg et al 2001). This can lead to a lack of statistical power when interpreting results (Morley et al 1999). Overall studies were limited by the poor quality of the studies, lack of standardised outcome measures and controls and inconsistency in the

effectiveness of treatments. Often the sample size and design of study made it difficult to arrive at a firm evidence based conclusion (Crawford and Laiou, 2007).

In summary it can be seen the literature on the rehabilitation of upper limb disorders is conflicting with insufficient evidenced based research to suggest its effectiveness. However there does appear to be some support for practical modalities such as exercise.

## **4.8 Application of back pain management principles to RSI**

### **4.8.1 HSE report on biopsychosocial management of RSI (2008)**

Research was recently commissioned by the HSE to review existing scientific evidence on the management of ULDs and to establish the extent to which it supported the use of a biopsychosocial approach to manage ULDs, as successfully used in back pain management (Waddell and Burton, 2004).

Burton et al, (2008) used a best evidence synthesis ('a review of reviews') to examine the literature related to upper limb disorders but found many methodological difficulties. They found the topic area of upper limb disorders was very broad encompassing both non specific diffuse regional pain syndromes and many clinically diagnosable conditions, some of which were prescribed industrial diseases which entitled people to Industrial Injuries Disablement Benefit. Inconsistencies were observed in the systems used to diagnose, label and classify RSI which together with confusing terminology had hampered epidemiological studies, treatment and management. Multiple terms were used to describe the same or similar conditions and the words used carried different meanings such as 'disorder' (which implied a known lesion) and 'complaint' (which highlighted the self reported nature of symptoms and their inherent subjectivity).

Based on their review of ULDs the report presented four key messages:

1. ULDs were commonly experienced irrespective of work. Although physical stress (minor injury) may trigger them, recovery and return to full activity

work was expected. Activity was considered helpful but prolonged rest was not;

2. Work was not the main cause of ULDs although undertaking some work might be difficult or impossible in the short term, but this did not mean work was unsafe. The term 'work relevant' was used to discourage the use of 'work-related'. It recognised work absence maybe necessary if job demands were intolerable;
3. Early return to work was considered an important factor in recovery. Health care professionals and employers were encouraged to facilitate work retention and return to work.
4. Co-operation from all parties was necessary to achieve successful outcomes in the form of shared goals, beliefs and commitment.

Burton et al, (2008) concluded that a biopsychosocial framework was very appropriate for managing ULDs because whilst biological factors were important, psychological factors were more important for vocational and disability outcomes. However, the authors cautioned that adopting such a biopsychosocial approach would require a radical shift in the way the relationship between work and ULDs was framed and handled. Educational strategies aimed at employers, workers and the public were considered to be the most useful way of facilitating this shift.

The report found multi-modal approaches offered more promise for vocational outcomes than either medical treatment or ergonomic workplace factors alone which should include interventions to address psychosocial issues.

The report concluded work was beneficial for health and all stakeholders needed to co-operate to facilitate early return to work or work retention by providing the necessary support and encouragement to overcome obstacles to recovery.

## **4.9 Pain management programmes in the UK**

Individuals who experience chronic pain without any discernible pathology despite trying various treatments may be referred to a multi disciplinary pain management programme (Main and Spanswick, 2000). Such programmes are common in pain



management and use cognitive behavioural therapy principles to identify and help change unhelpful beliefs, habits and thoughts which contribute to disability. These programmes aim to help the individual lead as normal as possible a life despite persistent pain, rather than focusing on alleviating pain (Main and Spanswick, 2000). They attempt to improve patients' physical functioning, their self efficacy in managing their pain and a resumption of valued activities including work. They discourage dependency on health care services and medication, alter maladaptive pain beliefs such as fear and avoidance of activity and reduce anxiety and depression (Main and Spanswick, 2000). The next section examines the underlying assumptions of cognitive behavioural therapy and its effectiveness in managing RSI.

#### **4.9.1 Cognitive behavioural therapy**

Cognitive behavioural therapy (CBT) is an important component of pain management programmes. Turk and Okifuji (2003) commented on the need to distinguish between the cognitive behavioural perspective and its outcomes which may be cognitive behavioural treatments. Turk and Okifuji, (2003) stated that the cognitive behavioural approach is based on the following five underlying assumptions:

1. Individuals actively process information rather than passively react to it;
2. Thoughts can affect mood, physiological processes, behaviour and have social consequences and vice versa;
3. Behaviour is a result of individual and environmental factors;
4. More adaptive ways of thinking, feeling and behaving can be learned;
5. Individuals actively contribute to changing their maladaptive thoughts feelings and behaviours.

CBT treatments are then used to address these underlying CB principles. Such approaches help individuals to re-conceptualise pain and suffering from being uncontrollable to something which can be managed and controlled and are provided

with the resources and skills to achieve this. The inter-relationships between thoughts, feelings and behaviours are explained to individuals as a basis for identifying and modifying maladaptive behaviours. The overall aim of CBT is to instill a problem-solving approach to help individuals better manage their pain (Turk and Okifuji, 2003). Individuals may also be made aware of how others around them, albeit unintentionally, may reinforce their maladaptive behaviours (Turk and Okifuji, 2003).

#### **4.9.2 Evaluation of CBT treatments**

Several authors have evaluated CB approaches with most finding some level of support for their effectiveness in reducing pain and improving physical functioning (Morley et al, 1999). Overall it appears that the CB approach has good support as a treatment modality by itself and in conjunction with other treatment approaches (Turk and Okifuji, 2003). Spence, (1989) investigated the effect of individual and group CBT treatment on chronic upper limb pain patients compared to controls who received no treatment. She concluded that both individual and group CBT treatments could produce significant long term benefits for sufferers of upper limb disorders. However, Spence's sample size was small with only 15 individuals in each treatment group, leading to difficulties in generalising from the study.

### **4.10 Management of RSI in the workplace**

#### **4.10.1 Prevention strategies for ULDs**

Preventing ULDs is a major challenge in occupational health practice (Piligian et al, 2000). As stated earlier within the EU, work related neck and upper limb musculoskeletal disorders need managing as they are a significant problem in terms of ill health and cost (Gauthy, 2007). Buckle and Devereux, (2002) stated key factors in reducing the problem of WRULDs were taking appropriate preventative measures and having systems in place for their early detection and rehabilitation.

#### *4.10.1.1 Workplace risk factors*

The many workplace risk factors which influence RSI development were already discussed in Chapter 3. As Burton et al, (2008) have indicated, neither ergonomic factors nor clinical management in isolation can effectively manage the RSI problem given its complicated aetiology involving both physical and psychosocial factors. In an epidemiological UK study by Sim et al, (2006) involving 10,000 adults to establish the presence or absence of ULDs, found upper limb pain to be associated with both physical and psychosocial factors. More significantly they found that work place modifications could prevent up to one in three cases of neck and upper limb disorders highlighting their important contribution to its overall management.

Whilst stress at work has long been implicated in RSI, its association with work has more recently received greater research attention (Devereux et al, 2004). Smith and Sainfort, (1989) identified five inter-related workplace factors believed to contribute to stress at work: the individual, the task, technology and tools, environment, and organisational factors.

In a cross sectional survey (n=3139), Devereux et al, (2004) identified potential risk factors for stress in musculoskeletal disorders to be a combination of individual factors (age, gender, beliefs, rumination) and physical (awkward position, repetition), and psychosocial (intrinsic and extrinsic effort, role ambiguity, role conflict). As we saw earlier, the neuromatrix theory suggested stress from injury could lead to pain and disability. This also has implications for its management as stress reduction and relaxation techniques to manage stress are used as part of clinical interventions.

Helliwell and Taylor, (2004) stated important strategies for work place management included active workplace surveillance, early intervention and an active management approach involving a multidisciplinary team. These authors advocated communicating with those on sick leave, the primary care physician and the workplace and which has more recently been endorsed by Burton et al (2008). Encouragement and the option to perform lighter duties may also help the individual return to work. An early review of any reported cases of arm pain lasting more than 4 weeks with major activity limitation is advocated. A work site assessment should be carried out and a rehabilitation programme considered for chronic cases (Helliwell and Taylor, 2004).

Despite this focus on prevention, as Spence, (1998) points out, the reality is that new injuries are still occurring and so prevention is not the sole solution.

In addition to receiving medical treatment and making occupational modifications due to RSI, individuals themselves play an important role in RSI management since they make many decisions regarding their own condition and the best way to manage it. For example, it is the individual who decides whether or not to comply with the medication prescribed or who seeks out additional information on the internet or uses alternative therapies at personal cost. The next section therefore considers how individuals manage their RSI and the strategies they use to cope with it.

#### **4.11 Self-management and coping in RSI**

Individuals often learn coping strategies through a process of trial and error and from family and their social surroundings (Main and Parker, 2000 in Main and Spanswick, 2000). Their adjustment to pain will depend in part on the extent of interference with valued activity (Rudy et al, 1988 in Main and Spanswick, 2000). Studies on RSI show that a wide range of treatment options are used by individuals from both orthodox and complementary medicine (Arskey, 1998; Reid et al, 1991; Calnan et al, 2005). An array of treatments used by individuals was reported in Reid et al's (1991) Australian study of the experiences of 52 women with RSI. In this study, the treatments used by the women included feldenkrais technique, ice packs, ultrasound, exercise and stretching, anti depressants, anti inflammatory drugs, splints, cortisone injections, acupuncture, physiotherapy, pain killers, sleeping tablets, spinal manipulation, fluid tablets, hydrotherapy, plaster cast, naturopathy, homeopathy, public hot baths, ray lamp treatment, iridology with the most common treatment being rest.

The treatments used by the women in Reid's study are very similar to those published on the UK RSI Association website which shows a similar tendency to delve into both traditional and complementary therapies along with general lifestyle changes.

In a qualitative study, Calnan et al, (2005) interviewed 47 men and women to evaluate health care received by them for upper limb disorders. They found the main health care priority for this group was pain alleviation rather than the need for a

diagnosis or other information. Respondents found treatments only partially effective and lead some individuals to avoid using both conventional and complementary health care. The integration of orthodox and non orthodox care within primary care services was advocated. Patients in this study adopted a pragmatic approach to treatment using whichever treatment proved most effective. However, the authors stated for people who had persistent pain and no cure, medical recognition and validation of their health problem became more significant. Whilst painkillers were routinely taken for pain, drugs were viewed as a short term solution to help tolerate symptoms.

Treatments however are only one aspect of how people manage and cope with illness. Individuals also make many other adjustments at work and home and draw on their own coping reserves to deal with the stress they face (Reid et al, 1991). People with RSI may respond to illness in different ways using active or passive coping strategies based on their health beliefs (Dorland and Hattie, 1992). This may include, talking to others, seeking information, avoiding activities etc. However a key point is that illness is a social event which requires support from different areas of people's lives including the workplace, health professionals, family and friends and wider society. These are important factors in considering its holistic prevention, management and rehabilitation.

## **4.12 Summary**

This chapter discussed the clinical and occupational management of RSI highlighting factors which impede this process such as the scarcity of strong empirical evidence for the efficacy of treatments, suggesting their use to be pragmatic rather than evidence-based. However, although strong evidence of the efficacy of RSI treatments is lacking, cognitive behavioural therapy and exercise appear to offer the most promise. Two principal factors complicating RSI management are its association with the workplace and the acceptance of diffuse non specific RSI as a genuine medical condition. The complex interplay between physical and psychosocial risk factors further complicates the occupational management of RSI. It was seen that the principles underlying back pain management including the use of a biopsychosocial framework to manage the

condition, are now also advocated for the management of RSI type conditions. Multi modal approaches rather than single modalities are considered more beneficial for the management of ULDs. Future efforts need to consider prevention as well as management since it is believed that RSI is largely preventable. However, as the recent HSE statistics mentioned earlier indicate and Spence, (1989) pointed out, new cases of RSI are still appearing and need to be managed. For these people, cognitive behavioural therapy appears to offer the greatest potential (Spence, 1989).

It was important to understand how RSI is managed since this has a major influence over how RSI is experienced by individuals which is the focus of this study. The topic of the next chapter takes us into a review of how illness has been investigated and conceptualised in the literature.

## **5 Chapter 5: Insiders' perspectives on chronic illness**

### **5.1 Introduction**

This chapter covers a selected review of literature on the illness experience in general and of RSI. The experience of illness sets in motion many changes which can affect all aspects of an individual's life and need to be understood if a patient is to be viewed holistically. There is an extensive body of literature which has focused on understanding what having a chronic illness means to the individual in the context of their everyday lives. Attention therefore is now focused on the literature on the personal experience of having a chronic illness, from the sufferers' perspective to review how chronic illness has been studied and conceptualised.

### **5.2 Aims of this chapter**

The aim of this chapter is to critically review the broad extant literature on the experience of having a chronic illness including key concepts which have emerged from the general chronic illness literature. Following this, the review will focus more narrowly on the experience of medically contested chronic illness and end with our current state of knowledge of the illness experience of RSI and to identify any knowledge gaps in the literature.

Chronic illness covers a broad spectrum of illnesses from endocrine, cardio respiratory to neurological and musculoskeletal disorders. It is neither possible, nor necessary to include all of these diverse conditions in this review. However some general literature on chronic illness will be covered along with RSI and similar medically contested musculoskeletal disorders such as Fibromyalgia (FM), Chronic Fatigue Syndrome (CFS) and non specific low back pain. In addition, seminal works of key authors who have studied illnesses outside this area have been included, such as Conrad's (1987, 1990) illness conceptualisations based on epilepsy and Bury's (1982) work on Arthritis. Greater attention has been paid to theoretical works

than purely descriptive studies. This chapter will also distinguish between what is meant by disease, illness and sickness with reference to health since these distinctions are important for conditions such as RSI where its medical status as a disease is disputed. Also included are the sociological concepts of Parsons' sick role, stigma and medicalisation as these are important in RSI.

This review will attempt to address how illness experience has been conceptualised and how this has evolved over time. It will consider which disciplinary perspectives and theoretical orientations have contributed to this body of knowledge on illness experience, which diseases have been studied and which have not and which methodological approaches and methods have been used to achieve this understanding. It will end with our current understanding of the RSI illness experience and highlight what gaps remain in our knowledge of the RSI illness experience.

### **5.2.1 Multi-disciplinary study of illness experience**

Reflecting the multi-dimensional nature of pain and chronic illness, the illness experience has been studied from different disciplinary perspectives including medical sociology, social psychology, anthropology, health sciences and for conditions such as back pain and RSI, occupational medicine and rehabilitation science. These disciplines are interested in understanding how illness affects individuals in order to provide more effective management which is paramount in long term chronic illness where the focus of care is on palliation as there is often no cure. It is now widely accepted that illness is socially constructed involving biological, social, environmental, emotional, cultural, economic and political factors (Brown, 1995). Given this complex nature, it is understandable that no single discipline has been able to capture all the various facets of illness experience. Rather the study of illness experience has benefited from these multiple perspectives since each discipline "sees" and illuminates different aspects of the multi-dimensional nature of chronic illness and chronic pain and makes its own valuable contributions to furthering knowledge and understanding of the chronic illness experience. The field of occupational health has more recently taken an



interest in the illness experience due to the negative impact of ill health on people's work identity and their ability to carry out paid work along with the need to rehabilitate people. Whilst the majority of literature reported on illness experience is based on researchers' interpretations of illness experiences as perceived by research participants, important insights have additionally been gained through the first hand illness experiences of sociologists such as Frank (1995), Toombs (1993), Rier (2000), Adamson (1997) and Sparks (2001). Anthropologists such as Jackson (1992; 2005), Kleinman (1988), Good (1992) and Ware (1992, 1993) have helped advance understanding of the illness experience in terms of the cultural context in which illness and pain occur.

Before looking at the illness experience, it is helpful first to define what is meant by the commonly used terms disease, illness and sickness.

### **5.2.2 Definitions of disease, illness and sickness**

Although disease and illness are related concepts, they are distinctly different entities (Idler, 1979; Radley, 1994). A disease is a biological-medical conception of pathological abnormalities in the body (Radley, 1994). Diseases are indicated by certain abnormal signs and symptoms analysed according to clinical definitions of disease (Idler, 1979; Kugelmann, 1999). Illness in contrast is the human experience of disease and is a social phenomenon with both an objective and subjective reality (Idler, 1979; Radley, 1994). A further difference is that Illness is considered to be socially constructed whilst disease is predominantly medically constructed. Sickness is the term used to refer to a social condition ascribed to people considered to be ill or diseased by others in society (Radley, 1994). This is important to bear in mind because illness does not occur in isolation, but is socially constructed. The social construction of illness and disease is highly significant for conditions such as RSI where its medical construction is still evolving which in turn affects its social standing, rendering it a medically contested disorder (Arskey, 1998). The medicalisation of RSI is mentioned next as it is important.

### **5.2.3 Medicalisation of contested illnesses**

Medicalisation is the process by which human, non-medical problems are defined and treated as medical problems (Mechanic, 1995; Conrad, 1992).

However, far more importantly for conditions such as RSI is the reverse process shown by Gerhardt (1990) where medicalisation has been strongly opposed to prevent conditions such as CFS falling under medical jurisdiction. Which diseases and conditions are legitimised by the medical profession has important implications for those suffering illness (Conrad, 1992) and is particularly pertinent to conditions such as diffuse RSI which has an uncertain status in biomedicine. These conditions are typically difficult to diagnose, often lack clinical signs and consequently are often delegitimised (Nettleton, 2006). Szabo and King, (2000) rejected the acceptance of RSI stating that scientific studies had not proved the connection between repetitive motion and injury. Barsky and Borus, (1999) maintained that RSI was a functional somatic syndrome characterised by various symptoms, suffering and disability rather than observable tissue pathology. They argued that somatic symptoms without pathological explanations were amplified by medicalisation whereby uncomfortable bodily states and isolated symptoms became reclassified as diseases for which medical treatment is sought.

### **5.2.4 The experience/interpretation of illness symptoms and medical signs**

Bodily sensations which interfere with an individual's intentions and draw attention to them are interpreted as symptoms. A symptom is defined by Kugelman (2003) as a subjective indication of illness, perceptible to the individual whilst a sign in medical terms is defined as objective evidence or indication of disease. This distinction between signs and symptoms is central to the dichotomies of subjective and objective, mental and physical, lay and expert used to account for health and illness (Kugelman, 2003). These dichotomies reflect underlying tensions between knowledge, power and professional status in the health care field (Kugelman, 2003:31). He argued that although both medical symptoms and medical signs were

important, in the medical setting, subjective experiences of symptoms were often ignored and priority given to medical signs (Kugelman, 2003)

Furthermore, Radley, (1994) highlighted that situational and social contexts influenced how symptoms were interpreted such that by the time a bodily feeling is thought of as a symptom, it has already undergone interpretation. Kugelman, (2003) provided a further example of how not all painful bodily sensations were interpreted as illness symptoms. Vigorous exercise or arduous digging in the garden may result in pain but this is not interpreted as illness symptoms, but rather as an indication of the hard work carried out.

### **5.2.5 The prestige hierarchy of disease**

How a disease is experienced by the individual is affected by its social significance (Bury, 1988 in Bury and Anderson, 1988). A Norwegian survey among physicians and final year medical students by Album and Westin, (2008) clearly illustrated the existence of a prestige hierarchy of diseases within the medical profession. Using a cross sectional survey of 242 senior doctors, 327 GPs and 317 medical students, these authors asked participants to rank 38 different diseases from 1-9 with 9 being the most prestigious. Myocardial infarction, leukaemia and brain tumour were among the highest ranked and fibromyalgia and anxiety neurosis were among the lowest. Diseases that hit abruptly had higher prestige than those which developed slowly and diseases without discernible objective signs were generally accorded low prestige. Diseases that could be effectively treated had a prestige advantage over those that could not. Studies of the social standing of medical conditions are not new to the social sciences, the concept of stigma (Goffman, 1963) has been used to analyse how people with certain diseases are socially evaluated in their interaction with doctors and others. This is important for diffuse RSI cases which lack objective signs of pathology and can lead to difficult health encounters.

### **5.2.6 Liminality**

While having a diagnosis is important in any illness, this need is intensified in contested illness where there are no discernable signs of disease (Peters et al,

1998; Page and Wessley, 2003). Achieving a diagnosis may be problematic because no objective signs of disease may be found. Where a diagnosis cannot be made, the individual may find him or herself in a difficult social position of feeling ill but may not be accorded a sick status (Madden and Sim, 2006). Jackson, (2003) has referred to this state between well and ill as a 'liminal state'. The lack of a diagnosis in such cases can deny individuals the status of being a legitimate patient. Hence a diagnosis is considered desirable and important, mainly because it enables a person to make sense of the disruptive experience of illness and enables them to consider how to manage and live with the symptoms (Broom and Woodward, 1996).

### **5.2.7 Factors contributing to increased illness experience research**

Research into the illness experience has proliferated over the past 25 years (Thorne and Paterson, 2000; Pierret, 2003). This increase has been attributed to several factors including the growing acceptance of the subjective view in medicine (Hyden, 1997) and the changing clinical goals of medicine which are more focused on patient-centred outcomes, so that "facts known only by physicians must be supplemented by values known only to the patient"(Sullivan, 2003). Other reasons cited for the increased interest were efforts to improve the cost effectiveness of medical care and the growing recognition that patients evaluated medical care within the context of their own lives, rather than in clinical settings, re-directing doctors' attention to patients' lives rather than their bodies (Sullivan, 2003). Chronic illness is also higher on the political, social and medical agenda due to the increased prevalence of chronic illness (Conrad, 1987). Chronic illnesses have become the most prevalent medical problem in Western medicine, supplanting infections and acute diseases (Gerhardt, 1989; Corbin and Strauss, 1985; Baszanger, 1989). Due to these changes, a greater proportion of GPs time is spent providing palliative care to chronically ill patients (Department of Health, 2004). Demographic trends and cultural assumptions about care and public services have added to the increased interest in illness (Bury, 1988 in Bury and Anderson, 1988). Conrad, (1990) suggested that medical sociology's orientation too had changed from aetiology and sick role conceptualisations to using sociological questions about medicine, illness and health. However, not all diseases have been studied to the same extent.

### **5.2.8 Which chronic diseases have been studied (and which have not)?**

The broad category of 'chronic conditions' is heterogeneous, encompassing different types of chronic illnesses (Bury, 1988 in Bury and Anderson, 1988). A 2004 UK Department of Health publication on Chronic Disease Management stated that chronic diseases in the UK were increasing, with currently 60% of adults reporting a chronic health problem. The common chronic diseases cited included: arthritis, heart disease, respiratory diseases, skin diseases, mental health problems, diabetes, epilepsy and chronic obstructive pulmonary disease (COPD). Furthermore, in the UK, around 25% of those with long term illness had three or more different problems, adding to the complexity of care. It follows that if these diseases are higher on the political agenda they may be more likely to be researched and attract research funding. At a social level, chronic illness is now so widespread that it is accepted as an inevitable and ordinary aspect of human existence, rather than an aberration (Bury, 1988 in Bury and Anderson, 1988). Changes have also occurred in which illnesses are categorised under the rubric of 'chronic illness', reflecting how what we consider to be a chronic disease has changed over time (Gerhardt, 1990). Kelly and Field, (1996) stated that sociologists have preferred to study 'exotic' illnesses such as epilepsy rather than common, often intractable conditions, such as back pain and stroke which consumed much of health professionals' time.

Conrad, (1990) remarked on the prominence of diseases in the literature where individuals had attended an outpatient clinic compared to those who did not, implying these were easier groups to target for research because of their accessibility. To redress this imbalance, Conrad, (1990) encouraged researchers to move beyond the clinical setting in order to gain a broader perspective of illness experience.

### **5.2.9 What is meant by chronic illness?**

Chronic illness generally exerts a long term effect on people's lives and since there are only limited options to treat the underlying condition, the emphasis of clinical care changes from curing disease to managing it (Bury, 1988 in Bury and Anderson, 1988; Thorne and Paterson 2000). Chronic illnesses vary from terminal cancer to

other illnesses which maybe long term, but not fatal. Verbrugge and Jette, (1994) argued that most commonly occurring chronic conditions such as arthritis, high blood pressure and chronic back pain are not fatal which meant that people generally live with chronic conditions rather than die from them. Conrad, (1987) differentiated between two main types of chronic illnesses. These were “lived with illnesses” which are usually not life threatening but which individuals have to adjust to and live with long term, such as epilepsy, diabetes and RA. Individuals with these conditions could lead relatively normal lives. Conrad, (1987) contrasted “lived with chronic illnesses” with “mortal chronic illnesses” where the illness was viewed as life threatening, such as cancer and heart attacks. One main difference between these were that some mortal illnesses could be cured or remitted, like breast cancer and once the emergency situation had passed, the illness could recede into the background, no longer featuring in their everyday lives. In mortal illness, the emphasis was on survival rather than the illness (Conrad, 1987).

Within Conrad’s subgroup of “lived with illnesses” (Conrad, 1990), is a particular group of illnesses whose symptoms defy medical explanation. The term used to describe this group is Medically Unexplained Symptoms (MUS), which was coined to refer to illnesses such as CFS, FM, some types of back pain and RSI as well as other conditions such as irritable bowel syndrome. All these conditions are medically contested, have an obscure aetiology and symptoms which are often difficult to diagnose, treat and manage (Nettleton, 2006; Peters et al, 1998; Dumit, 2006). Due to their ambiguous medical status, MUS often carry elements of stigma and delegitimation (Asbring and Narvanen, 2002) and are problematic for both sufferers and health care professionals, (Asbring and Narvanen, 2002, 2003; Calnan et al, 2005). These MUS create uncertainty and anxiety because sufferers of these conditions occupy a position in which they are neither well nor ill (Bury, 1988 in Bury and Anderson, 1988). Hence MUS are experienced differently to illnesses which are medically accepted, well established and undisputed such as RA, cancer and diabetes. It is therefore worth exploring the experiences of living with a contested illness, since these are likely to be more similar to the RSI experience.

### **5.2.10 Search for meaning in illness**

Authors such as Radley, (1994) have highlighted the importance for individuals to make meaning or sense of illness. Bury, (1988) stated that underlying an individual's search for an explanation, is the search for meaning (Bury, 1988 in Bury and Anderson, 1988). When illness occurs and inevitably disrupts people's 'taken for granted lives' (Bury, 1982), they search for an explanation as a way of making meaning of their illness. According to Bury, illness is always experienced at two discrete levels; at a personal level and a wider societal level through interactions with others (Bury, 1988 in Bury and Anderson, 1988). Illness has meaning for the individual because of its consequences on their daily lives and meanings as significance which related to what the condition signified to others (Bury, 1988 in Bury and Anderson, 1988).

When ill, individuals often seek medical help to find out what is wrong with their body and for some remedy for it. Part of that search involved wanting to know the cause of their distress and symptoms (Radley, 1994; Bury, 1988 in Bury and Anderson, 1988). This often required a diagnosis which is routinely carried out in modern medical practice (Brown, 1995). In Western cultures people and organisations such as employers and insurers are unwilling to accept a person's claims to be sick without medical certification to validate the person's claims of illness (Woodward, 1995). Even friends and family may remain sceptical until medical legitimisation is given (Broom and Woodward, 1996). Parsons' sick role places an obligation on those ill to seek medical help and treatment to enable them to resume normal roles and responsibilities as quickly as possible (Parsons, 1951). Gerhard, (1989) interpreting the social order, stated one of the main objectives of the health care system is to provide a diagnostic label to legitimise a person's claim to be sick. Patients too often expected this, as seen in Blaxter's 1983 study.

Central to illness and making meaning is to answer the question about what is wrong with the body (Pierret, 2003). To answer this, individuals often sought help from medical professionals, which often included a diagnosis as a form of medical legitimisation in which medicine verified that something was wrong, and provided a basis for treatment. Frank, (2001) stated that attaching a diagnostic label to a person's name transformed them from a person with symptoms into a patient, a

process termed medical legitimization, meaning the person's behaviour was medically verified as warranted.

#### **5.2.11 Experience of illness without disease**

In chronic conditions such as cancer, diabetes or arthritis where both objective clinical signs and subjective symptoms are present, the process of diagnosis can be relatively straight forward (Broom and Woodward, 1996). In cases of conditions such as hypertension, whilst objective signs may exist, there may be no accompanying symptoms so the individual may be aware of having the condition.

However, in conditions such as diffuse RSI, CFS, FM, achieving a diagnosis may be problematic because no objective signs of disease may be found, despite the individual's subjective experience of distressing and persistent symptoms (Arskey, 1998; Reid et al, 1991). A lack of a diagnosis denies these individuals the status of being a legitimate patient. Where a diagnosis cannot be made, the individual may feel ill but is not conferred a 'sick' status (Madden and Sim, 2006). Jackson (2005) referred to this position, in between 'well' and 'ill', as a 'liminal state' whereby the symptoms persist but no diagnosis can be given (Jackson, 2005). Hence, a diagnosis is important in enabling the individual to make meaning of the disruptive experience of illness and to consider how they will manage and live with the symptoms (Broom and Woodward, 1996).

### **5.3 Foundation work on understanding the lay perspective on illness**

#### **5.3.1 Doctor/patient accounts in chronic illness**

There is a growing body of research which suggests that professionals and patients accounts of illness differ significantly which has implications for patient care (Broom and Woodward, 1996; May et al, 2004; Asbring and Narvanen, 2003). This literature suggests that there is often a mis-match of views between patients and health professionals.



Our current understanding of lay experience of health and illness has increased significantly over the past 25 years based on the foundations laid by authors such as Bury (1982, 1991), Charmaz (1983), Baszanger (1989, 1993), Williams (1984), Conrad (1987, 1990) and others. Despite the lapse of over 25 years since the formulation of some of these concepts, they still remain in use today. This early body of knowledge has been considerably enlarged in addition to increases in the diversity of illnesses studied. Although some of these studies focused on one specific disease, others aggregated chronic pain experiences from different conditions on their presumed underlying similarities (Thorne et al, 2002). Examples of studies which have aggregated chronic illness experiences include Honkasalo (2000), Baszanger (1989) and Hilbert (1984). Others have chosen to focus on one particular disease such as epilepsy (Schneider and Conrad, 1983) or arthritis (Bury, 1982).

Studies of illness experience in the 1960s and 1970s were heavily influenced by Parsons' conceptualisation of illness as a particular form of social deviance based on Parsons' sick role concept (Parsons, 1951).

### **5.3.2 The influence of Parsons' 'sick role' on illness experience**

Parsons' conceptualisation of illness as social deviance has been highly influential in the theoretical conceptualisation of illness (Gallagher, 1976; Shilling, 2002; Williams, 2005).

Parsons, (1951) viewed illness mainly as a problem of social control (Waitzkin, 1971). Illness is seen as an undesirable deviance (departure from conformity with the normal standards) that interferes with people's ability to fulfill their social roles and responsibilities and must therefore be controlled (Parsons, 1951). The sick role is considered to be a motivation-based system devised to accommodate and control illness in an acceptable way (Waitzkin, 1971). The sick role discourages the secondary gains of illness (Williams, 2005). Parsons viewed the individual as a biological system whose normal functioning was disturbed by illness and included the personal and social adjustments individuals needed to make to regain health

(Parsons, 1951). In Parsons' formulation, the social system functions to preserve the collective health of society. The responsibility for controlling health is delegated to doctors who permit or restrict access to the sick role as agents of social control.

The rights (1 and 2) and obligations (3 and 4) inherent in the sick role are the following (Segall, 1976; Williams, 2005):

1. Illness is involuntary and the individual is not held responsible for it;
2. The individual is temporarily relieved from normal role responsibilities;
3. These exemptions are conditional on the individual's efforts to regain health;
4. Technically competent help must be sought, usually from a physician, to help sufferers regain good health and to re-integrate them into social life as quickly as possible.

### **5.3.3 Criticisms of Parsons' sick role theory**

Williams, (2005) credited Parsons with extending thinking beyond biomedicine's narrow view of illness as arising from mechanical malfunction only, but Parsons' theory has also been criticised because of his interpretation of the patient role which gave doctors the authority to legitimise illness and has resulted in an unequal doctor–patient relationship. Moreover, the model has limited applicability to chronic illnesses that are often incurable and may be permanent deviations from 'normal behaviour' as individuals may be unable to return to productive function (Williams, 2005; Gallagher, 1976). However, despite these criticisms, the sick role remains a powerful concept in the literature.

The 1980s saw a change in the way illness was conceptualised and saw the emergence of some key sociological concepts which have provided the framework for subsequent studies on illness experience. These include the work of Corbin and Strauss (1985), Bury's (1982) conceptualisation of biographical disruption, the loss of self as conceptualised by Charmaz (1983), biographical reconstruction as

proposed by Williams (1984) and meanings at risk conceptualised by Bury (1988). Corbin and Strauss' work in the 1980s offered a change in direction from Parsons' illness deviance model. Corbin and Strauss, (1985) identified the individual tasks which comprised the large amount of work involved in managing illness and studied how these were carried out and by whom. Work had to be carried out to maintain relationships, follow medical regimens, control symptoms and biographical work. The majority of this work contributed to maintaining the illness trajectory and maintaining people's everyday lives.

## **5.4 The insider's perspective**

A significant breakthrough in understanding the illness experience has been the legitimacy and acknowledgement of the importance of the insider's perspective, arguably driven by a more patient- centred approach. The move away from viewing illness as deviance as formulated in the Parsonian sick role has encouraged new conceptualisations (Lawton, 2003). The insider's perspective of illness experience has enabled greater insights into emotions to be gained which were less amenable to access using quantitative surveys and the uncovering of concepts such as uncertainty and the study of the impact of illness on self and identity (Charmaz, 1983; Baszanger 1989). Conrad, (1990) stated that illness could be studied from two principal standpoints: an outsider's (emic) or insider's perspective (etic), recognising this was an oversimplification. Outsider perspectives viewed illness from outside the experience itself, minimising or ignoring the subjective reality of the sufferer. The best-known outsider approach to illness was Parsons' sick role but also covered most studies of illness behaviour. The outsider perspective was deductive with a focus on medical or social questions, generally adopting a doctor-centred view of illness in which receipt of medical care took priority over the personal experience of illness. In marked contrast, the insider's perspective studied illness experience in a more inductive manner, focussing directly on the subjective experience of living with and in spite of illness (Conrad, 1990).

Many authors have emphasised the need for more research into the patient's perspective. Embedded within patient narratives is valuable knowledge about the meaning and significance of illness which is essential for effective clinical practice

(Charon, 2001). Garro (1992) stated that much of what people said in narratives related to maintaining a sense of self and purpose in the face of the disruption caused by illness. Illness changed people's life plans (Garro, 1992) but to view chronic illness only in term of loss is an oversimplification.

Not all illnesses are experienced in the same way. More established and accepted illnesses such as arthritis or diabetes are experienced differently to medically contested illnesses. In contested illnesses sufferers experience symptoms but show no discernible signs of disease. When the reality of the pain experience is questioned by medical professionals and others, this represents a threat to their self integrity. By attributing the pain to a malfunctioning mind rather than body, blame was placed on the sufferer for the pain.

Table 5.1 provides examples of research into contested illnesses such as FM and CFS which have taken an insider's perspective and lists some of the themes the authors found. Despite the wide range of approaches taken in these studies and the slightly differing focus of each sample, the experience of contested illness merits attention in this review since it shares many similarities with RSI.

**Table 5.1: Summarised themes from Fibromyalgia and Chronic Fatigue Syndrome literature**

<b>Main Themes</b>	<b>Sub themes</b>	<b>Supporting references</b>
Being discredited and delegitimation	Not being believed Negative diagnostic tests Invisible symptoms Symptoms trivialised/normalised Condition not taken seriously Conceal illness to pass as "normal" Complaints psychologized or told do not exist Stigma (malingering, depression, psychological disorder, no objective signs) Symptom severity not acknowledged Veracity of symptoms doubted	Broom and Woodward, (1996) Henriksson, (1995) Madden and Sim, (2006) Ware, (1992) Clarke and James, (2003) Guise et al, (2007) Asbring and Narvanen, (2002) Soderberg et al, (1999) Paulson et al, (2002) Dickson et al, (2007) Deale and Wessely, (2001)

	Being judged by others	
Threats to integrity	Existence at stake Lack of knowledge and attitude of others	Raheim and Haland, (2006) Travers and Lawler, (2008) Madden and Sim, (2006) Clark and James, (2003) Soderberg et al, (1999) Ware, (1992)
Changes to identity	Profoundly different and changed self, Loss of self Creation of better self more reflective self Balancing illness gains and losses Lowering expectations /demands of others and self	Asbring and Narvanen, (2002) Paulson et al, (2002) Asbring, (2001) Broom and Woodward, (1996) Travers and Lawler, (2008) Schaefer, (1995)
Searching for meaning /explanation diagnosis	Help seeking from multiple doctors, specialists Wanting a diagnosis and name for illness Wanting medical validation Doctors dismissive, Search for "good doctors" Diagnosis with held and self diagnosis treatments largely ineffective Resort to alternative health care and self treatment Search to alleviate pain Search for understanding	Travers and Lawler, (2008) Broom and Woodward, (1996) Madden and Sim, (2006) Henriksson, (1995)
Ambiguous medical status of condition/ Medically disputed nature	Creates uncertainty Condition poorly defined and understood Condition has mysterious label which is belittled Empty diagnosis, conferred no meaning Medical uncertainty affected achieving a diagnosis blame apportioned if not medically legitimised FM/CFS Low prestige status Cant be objectively diagnosed Difficult to treat Negative attitude of others posed threat to integrity	Raheim and Haland, (2006) Dickson et al, (2007) Broom and Woodward, (1996) Ware, (1999) Clarke and James, (2003) Asbring and Narvanen, (2002)
Consequences of bodily pain/illness	Intrusive symptoms, pain and fatigue overwhelm , disrupt life and mobility Daily self care, dressing, washing, grooming Loss of physical and mental capacity (concentration, memory) Altered relationships Lost/changed physical action, ability "to do" unpredictability made planning ahead difficult	Henriksson(1995) Soderberg et al, (1999) Paulson et al, (2002) Cudney et al (2002) Ware, (1999) Raheim and Haland, (2006)

	<p>affected social roles e.g. parenting, work</p> <p>Increased dependency on others</p> <p>Loss of control and freedom to live life as before</p> <p>Restricted life and confined to limited spaces</p> <p>Life planned around illness</p> <p>Created financial insecurity</p> <p>Illness gains</p> <p>Sleep disturbance/depression</p> <p>Constantly having to convince others</p> <p>Emotional changes, irritable, frustrated, angry, guilt, uncertainty,</p>	
<b>Isolation</b>	<p>Rejecting others - self imposed social withdrawal, no energy for social participation</p> <p>Rejection by others</p> <p>Emotional and physical dimensions</p> <p>Pain talk socially undesirable - alienates others</p>	<p>Ware, (1992, 1999)</p> <p>Cudney et al, (2002),</p> <p>Raheim and Haland, (2006)</p>
<b>Adaptation/ coping strategies</b>	<p>Pacing, defining boundaries and learning to live within body's limits, being flexible, creating new routines, change ways of doing things</p> <p>Finding positive aspects of the experience.</p> <p>Gaining knowledge and expertise</p> <p>Delegating to family members</p> <p>Educate others</p> <p>Change from eradicating to managing symptoms</p>	<p>Henriksson, (1995)</p> <p>Travers and Lawler, (2008)</p> <p>Soderberg et al, (1999)</p> <p>Asbring, (2001)</p> <p>Clarke and James, (2003)</p>

These studies on medically contested musculoskeletal conditions such as FM/CFS have used different approaches to access the illness experience. Approaches used included the 'lived with' experience of illness (Raheim and Haland, 2006; Henriksson, 1995; Paulson et al, 2002), the experience of self in illness (Travers and Lawler, 2007; Clarke and James, 2003), biographical disruption (Asbring, 2001) and creating meaning in illness (Madden and Sim, 2006). In addition, a few authors focused on how illness is constructed and medicalised (Ware, 1992; Arskey, 1998; Broom and Woodward, 1996). Asbring and Narvanen's (2002) study focused on stigma amongst women with CFS and FM. One study reported on a clinical intervention aimed at reducing physical isolation during illness (Cudney et al, 2002) whilst another served the dual purpose of assessing the utility of the internet in accessing illness experience accounts and studied how individuals constructed their

illness. The sample size varied from 12 – 68 in these studies with the majority of participants being females and several consisting exclusively of females. Only one study involving 14 males was devoted solely to the male perspective (Paulson et al, 2002). In these studies participants were assumed to have chronic pain with some authors specifying how they defined this. The duration of pain was usually long standing ranging from one year to 36 years. The age of participants ranged from 13- 80 but the majority of participants were in their 30s and 40s. The majority of the samples were clinically derived, often through rheumatology pain clinics or GPs. Three of these studies were internet based and three had included a few individuals who had recovered (Broom and Woodward, 1996; Ware, 1999; Travers and Lawler, 2007).

In all these studies (except for Deale and Wessley, 2001) the qualitative paradigm was used as this was conducive to eliciting insights into people's experiences. The most common method used in the studies was face to face, one to one, semi-structured interviews, with participants usually interviewed once for between fifteen minutes and two hours. A small number of studies conducted multiple interviews. One study used focus groups in conjunction with other methods. Interviews were usually tape recorded and transcribed verbatim. Methods used for analysis varied but consisted mainly of thematic analysis, grounded theory and IPA.

A strength of Broom and Woodward's (1996) study was that both the sufferers' and health practitioners' views were obtained about CFS. This study was based on interviews with 47 sufferers and 20 GPs. The GPs were felt to dismiss symptoms, defined CFS in a psychiatric framework implying it was all in the mind, and this medical interpretation exacerbated sufferers' uncertainty and alienation. Individuals with CFS felt they were unheard and their symptoms ignored. 86% of those who were ill without a diagnosis said they felt more sick. Sufferers felt judged and dismissed by others and since they couldn't behave as before, they lost their sense of identity and had low self esteem (Broom and Woodward, 1996). Some of the studies aimed to provide rich description, whilst others used a greater level of abstraction and interpretation and made efforts to integrate themes. A small number of studies had used the internet for research either on its own or in conjunction with face to face data collection. One study which had used internet and conventional research methods found that the data from both sources were very similar lending weight to the utility of the internet for accessing insights into personal illness. Some

authors have conceptualised illness in terms of the stages that the individual passes through during illness and analysing what happens at each stage. Reid et al, (1991) and Calnan et al, (2005) have adopted this approach using the stages of illness onset, illness action and adjustment to illness. Whilst Reid et al, (1991) gave a comprehensive analysis of all three stages which were published in two papers; Calnan et al, (2005) limited their study to the illness action stage since the focus of their research was to understand sufferers' help seeking behaviours. Their study was part of a larger quantitative survey to establish the prevalence of upper limb disorders in the population.

A few studies of illness experience were part of a larger mixed method study. Whilst some studies tried to provide broad insights into the overall illness experience such as Henriksson (1995) others have studied narrower aspects of illness such as how the self changes in illness (Asbring, 2001). The meaning of illness has been the focus for some studies (Madden and Sim, 2006) and the meaning and experience of symptoms has also been studied (Johansson, 1999). Pain features in all these studies due to its consequences for the individual in terms of restricting their life by, for example: reducing their capacity for paid work, affecting their ability to carry out social roles or affecting their ability to manipulate the body so that movements such as lifting, carrying, lying and sitting become problematic.

Some authors have tried to provide rich data and its interpretations, which for limits of space in journal publications have spread the study over two papers. In some cases this has worked (Henriksson, 1995) but in others cases the individual's experience of illness is fragmented and fails to provide an integrated account of the illness experience (Asbring, 2001, Asbring and Narvanen 2002).

Different levels of analysis and abstraction were undertaken depending on the author's aims. Some did little more than to report the findings and made no attempt to relate their studies to other work. This is important if the studies are to have greater utility to advance knowledge generally by relating findings to other research. Others aimed to provide detailed descriptions missing out on the opportunity to widen understanding.



Others still just reported themes without integrating them (Walker et al, 1999). A significant number of studies recruited patients from clinical settings (e.g. pain clinics, GP etc.). There has been criticism of the heavy reliance on clinical settings and the need to move away from this. Part of the problem is that what is reported is sometimes a part of a larger study which was established for some other purpose. The qualitative papers then become just an adjunct to another study rather than a real focus on that topic (Calnan et al, 2005).

A further change has been the increasing use of the internet for health care research. This has proved to be a fruitful area for exploring and understanding health related problems. Internet studies conducted include Glenton, (2003); Guise et al, (2007); Barker, (2008) and Dumit, (2006).

Some authors considered the different settings in which illness occurred; work, home or confined within the walls of a room. Illness involves major disruption both biographical and to the organisation of daily life. Relationships become altered as the individual is unable to contribute to activities of daily life such as cleaning, cooking and driving which must then be delegated to others. In recognition of the shared burden of illness, Corbin and Strauss (1985) interviewed 60 couples on the basis that it was usually the spouse who was most affected.

## **5.5 Use of qualitative approaches to study illness experience**

Since the experience of chronic pain is determined by the individual's specific context and the meaning they give to pain, it is important to conduct qualitative studies to gain deeper understanding to access those meanings. Qualitative studies offer a range of tools that can be used to explore the personal experience of RSI. Bendelow and Williams (1995) stated that whilst the medical voice was an important one, that of the subjects should not be forgotten. They advocated using social and phenomenological approaches to increase knowledge and understanding of pain (Bendelow and Williams, 1995).

### **5.5.1 Useful concepts for understanding the illness experience**

Whilst disease specific knowledge is both necessary and useful for understanding a specific illness experience, greater advances in overall understanding of the generic illness experience have emanated from studies where authors have extended their conceptualisation beyond the confines of their own particular study, in attempts to make it applicable to other social groups. One example of this is the concept of uncertainty which has been shown to accompany most illness experiences (Baszanger, 1989). A further example of this is Bury's concept of biographical disruption (1982) which is still used today, 25 years after its formulation. For example, Dickson et al, (2007) used the concept of biographical disruption and loss to interpret the experience of individuals with spinal cord injury. Other general concepts developed and still widely used include the "loss of self" proposed by Charmaz, (1983).

Illness experience has been studied using the qualitative paradigm usually in the form of semi-structured interviews which are designed to facilitate the patient telling the story of their illness in their own words (Mattingly and Garro, 1994; Reismann, 1990). However, Radley (2005) stated that in telling stories, people revealed not only life events but also insights into suffering and living with disease and its consequences. Illness stories can allow health professionals to vicariously experience a world which they may not have experienced themselves (Radley, 2005). Illness accounts provided insights into people's different journeys through illness. Frank, (1995) stated that illness narratives can reveal the stark reality of what it means to live with bodily dysfunction. Garro, (1992) stated that the interviews she conducted with people with temporomandibular joint disorder (TMJ) were not only illness stories but moreover stories of "a life altered by illness" (Garro, 1992: 101). In addition, Mattingly and Garro, (1994) stated narrative accounts of illness and healing were important because they allowed individuals to communicate and give meaning to their experience. However, Robinson, (1999) pointed out that researchers must be clear that narratives represent the perceptions or interpretations of the people living the illness phenomenon which are then interpreted through the eyes of the researcher, giving a second order account of the phenomenon.

## **5.6 Methods used to understand illness experiences**

The basic semi-structured interview technique has stood the test of time and remained popular. However, the forms the interview takes has changed, such as narrative analysis and 'retrospective story telling' are widely used to understand the meaning people give to their illness in relation to their social world. Thorne and Paterson, (2002) stated that considerable changes had occurred in the way chronic illness was viewed. From 1980-1990 the emphasis of illness experience was on the negative aspects of illness, such as loss and burden. A more optimistic approach became evident in later years including positive aspects of illness such as hope and the positive gains which could result from illness (Thorne et al, 2002; Asbring, 2002; Clarke and James, 2003).

### **5.6.1 The emergence of online/virtual narratives**

Another more recent change has been that individuals have turned to the internet to tell and share their illness stories. The opportunities afforded by the internet to use non-intrusive research methods such as the analysis of archived e-mails (Murray and Sixsmith, 1998; Sixsmith and Murray, 2001), home pages published on the web (Hardey, 2002) and interactive research have resulted in an increasing number of studies.

### **5.6.2 Biographical disruption**

Bury, (1982) studied 30 patients with emerging RA, attending an outpatient clinic for the first time. Bury, (1982) highlighted the shock felt by some young women on discovering that they could get RA as this was unexpected at their young age.

Bury, (1982) conceptualised chronic illness as a particular form of disruptive event, which he termed 'biographical disruption' (or using Giddens' (1979) term, critical situation). Giddens' (1979: 123) stated that much could be learned about daily life by "analysing circumstances in which those settings are radically disturbed". He called these circumstances a "critical situation" and defined this as "a set of circumstances - which for whatever reason - radically disrupts accustomed routines of daily life" (Giddens, 1979:124). Giddens' original notion of critical situation referred to the

radical social change brought about to society by large scale events such as war, political revolution, rapid industrialisation and the disruption caused when traditional cultures encountered advanced societies (Giddens, 1979). Bury extended Giddens' term to chronic illness on the premise that in chronic illness, the structures of everyday life and the foundations of knowledge on which they were based, were also disrupted. Bury, (1982) stated that chronic illness also disrupted relationships since the ill often became more dependent on those around them. Bury, (1982) contended that chronic illness forced individuals to re-evaluate their future expectations and plans.

Bury's (1982) biographical disruption concept has proved to be a useful tool. However, Williams, (2000) suggested these prevailing concepts should periodically be challenged to test their relevance to developing research. Bury's concept of biographical disruption has been refined and challenged. Some authors have argued that disruption may be anticipated in older people rather than unexpected (disruptive) (Richardson et al, 2006). Other authors have conceptualised illness as biographical reinforcement in the case of AIDS (Carricaburu and Pierret, 1995), or biographical flow rather than disruption (Faircloth et al, 2004) whilst Asbring, (2001) found that biographical disruption could be partial rather than total and Honkasalo, (2000) found disruption to be continuous.

### **5.6.3 Health within illness – the dynamic nature of illness**

Several studies of illness experience have conceptualised illness as a dynamic process. For example, Bury, (1982) emphasised the fluid boundaries between health and illness when patients vacillated between periods of well being interspersed with feeling unwell. He explained that a chronically ill person could make adaptations to their general life but still assume the sick role when medical intervention was used or when conditions suddenly deteriorated. This concept has similarly been used by Thorne and Paterson, (1998) who proposed a "shifting perspectives model of illness" in which the ill person could change between periods of being well and being ill. More recently Travers and Lawler, (2008) used this concept of constant movement between illness and health to explain the experience of CFS. They defined the overall experience of having CFS as "the struggling self seeking renewal" which encompassed four criteria which had to be met before the individual could regain health. These involved letting go of untenable images of self, accept that illness would be long term, engage in self reflection and find positive

meanings in illness and pursue new valued activities. The tensions and fluctuations between these two states formed the basis of CFS patients' struggle.

Another conceptualisation based on the dynamic nature of illness was the fluctuation experienced by the individual of feeling well and ill which was described as having "good days and bad days" (Charmaz, 1991) in which relatively normal 'good' days could suddenly be transformed into bad days where the individual could be in excruciating pain without any apparent logical explanation. Also considered important was how the individual conceptualised time. In view of this, the dimensions of space and time have also been used to study illness. Such studies have shown how chronological time alters in illness (Charmaz, 1991). In her study, sufferers' spoke of "long lasting days".

One interesting recent study showed how the world of an individual could become so restricted by illness and pain that their 'space' became confined to the walls of their house or even a room (Raheim and Haland, 2006). Overwhelming pain was shown to make even negotiating movement between the kitchen and the living room an enormous task requiring careful planning to ensure that the journey could be undertaken using support from walls and surrounding objects to lean against (Raheim and Haland, 2006). Getting out of the house for these individuals was unimaginable since just getting from one room to the next was such a major feat and thereby confined their world and space.

Illness has also been studied by following its natural course through three phases: illness onset, illness action (what people do about symptoms, e.g. seek medical help), and adjustments people make in response to illness. This focuses on how individuals first recognise symptoms and interprets them, to what they do (or don't do) about them, to their medical help seeking efforts and how they cope with and adapt to illness. This conceptualisation, used by Reid et al, (1991) and Calnan et al, (2005) can provide insights into people's experiences including decision making processes and the explanations people give for their symptoms.

## **5.7 Factors affecting the illness experience**

Many contextual and mediating factors influence how an individual responds to and experiences chronic illness and pain (Charmaz, 1995). Thorne and Paterson, (2000)

stated that the personal, medical and social way disease is constructed influenced how people experienced it.

### **5.7.1 Gender**

Important mediating factors include the person's age, gender, stage of life and ethnic background (Charmaz, 1995). While men and women are known to experience illness differently, most of the research into chronic illness has focused on women's illness experiences (Thorne and Paterson, 2000). In one of the few studies on men's experiences, Charmaz, (1995) found that men were unwilling to adopt the identity of an ill person. She attributed this to the role of men in Western society which expected them to be strong and so being seen as weak or vulnerable was considered undesirable.

### **5.7.2 Psychological versus physiological origins of illness influences experience**

The mind/body dichotomy continues to exert considerable influence over how people experience illness (Price, 1996; Bates et al, 1997). Thorne and Paterson, (2000) stated that whether a disease is believed to have a physical or mental origin has important implications for how it is experienced socially and psychologically by the individual. Furthermore, Charmaz, (1991) pointed out how medical treatment can also affect how chronic illness is experienced.

### **5.7.3 Discredited illness and stigma**

As an example of the different way illnesses are socially experienced, discredited diseases such as epilepsy (Scambler and Hopkins, 1986) are experienced differently from those that do not carry social stigma such as RA (Thorne and Paterson, 2000). Thorne and Paterson, (2000) further argued that diabetes and heart disease, which are well understood, elicit a different social response to conditions such as FM and CFS, which currently appear to have no physiological basis.

Culture and historical period are also important factors that can influence illness experience (Conrad, 1987). People's belief systems, moral implications, explanatory models, conceptions about body and spirit, and medical knowledge could all contribute to culturally different illness experiences (Conrad, 1987).

#### **5.7.4 Treating chronic illness within an acute care model**

Chronic illness is often treated within the same model as acute illness (Baszanger, 1989); (see chapter 2 on pain). One of the main problems with using the same model for managing chronic illness is the assumption of the acute model that patients should expect rapid recovery (Charmaz, 1991). Chronic conditions however have to be managed over a long period (Baszanger, 1989). Despite this Baszanger, (1989) stated that hospital staff continued to manage chronic illness within an acute care framework and remained disease-focused. Moreover, many individuals with chronic illness also treated their illness as if it were acute. The acute illness model of managing chronic illness is now considered inappropriate (EFIC, 2001; Mechanic, 1995). As stated earlier chronic pain syndromes are better managed within a biopsychosocial model.

#### **5.7.5 Balancing losses and gains in illness**

While illness changed people's life plans, to view chronic illness only in term of loss is an oversimplification (Garro, 1992). Illness is not always only about loss, although that is the most evident aspect in response to the disruption caused by illness. Shaefer, (1995) argued that over time people struck a balance between the negative aspects of illness and the positive gains. It is argued that finding positive aspects of illness is a way of giving meaning to it (Asbring, 2001; Frank, 1995; Pierret, 2003; Kleinman, 1988).

#### **5.7.6 Uncertainty**

People with medically unexplained symptoms (MUS) are said to experience illness in the absence of disease and because of this, they are denied permission to be ill leading to 'embodied doubt and uncertainty' (Nettleton, 2006: 1167). MUS are typically difficult to diagnose; with the pre-diagnostic stage being particularly problematic as sufferers are in diagnostic limbo (Corbin and Strauss, 1985). MUS created existential uncertainty for both patients and doctors (Adamson, 1997). In contested illness uncertainty centres on the diagnostic label (Ware, 1992). Fox, (1980), Fox and Rainie, (2000) claimed that the more technologically advanced medicine became, the less people were able to abide clinical uncertainty.

Conrad, (1987) stated that the self became unsettled when the body was altered during illness, creating uncertainty in self. The self is dynamic (Clarke and James, 2003) and constantly changes in response to how the person perceives their own identity or that attached to them by others (Charmaz, 1987).

## **5.8 What is our current state of knowledge about the RSI illness experience?**

Research into the illness experience of RSI is limited. Reid et al's (1991) study, "Pilgrimage of pain", remains a landmark study providing a comprehensive account of the illness experience of 52 women drawn from two sectors of the Australian workforce; a meat processing factory and a telecommunications company. The findings from the study were disseminated via two related research papers of which the above is more widely quoted than the related paper by Ewan et al, (1991) 'Falling out of culture' which reported the consequences of having RSI and how the women coped. These authors conceptualised the illness experience of RSI in terms of three key stages: illness onset, illness action (help seeking) and adjustment. Reid et al's (1991) paper provided comprehensive coverage of these women's help seeking activities. These women with RSI saw a variety of health professionals including GPs, specialists such as rheumatologists and orthopaedic surgeons as well as representatives from insurance companies who came to assess their compensation claims. Seeing representatives of insurance companies became a terrifying experience for these women. Their encounters with insurance companies became a 'public performance' which had enormous significance for them since their future financial security often depended on their outcome. Some women described this experience metaphorically as being like they were taking an exam, in which their body was the exam paper.

Reid et al's (1991) study was undertaken at a time when medical and legal efforts were focused on defining, describing and disputing RSI, with little interest in the lives of sufferers. They provided a compelling account of the profound impact RSI had on the lives of the female respondents. RSI impinged upon both the women's' work and private lives confronting them with unemployment, strained relationships, financial hardship, reduced participation in leisure activities, a changed future, lowered self



esteem together with emotional and mental distress. Their 'pilgrimage' for caring, treatment and moral affirmation was dominated by their need to be believed and establish their personal integrity. Central themes which emerged from the female RSI sufferers experiences were: the lack of clarity surrounding RSI, uncertainty over future prospects and the negative consequences of disbelief of others on their self identity. The essence of these women's experience entailed a re-configuration of life roles, managing altered relationships and adjusting their lives to incorporate the limitations imposed by RSI. The data for Reid et al's (1991) study was from two questionnaires; the first questionnaire collected standardised personal history and work data whilst the interviews based on the second questionnaire centred on the illness experience. The interviews lasted 1-3 hours in which the women were encouraged to speak freely about issues which had meaning and significance for them. The interviews were transcribed and a content analysis was carried out which focused on explanatory models, illness experience, help seeking behaviour and the medico-legal system. All 52 women had RSI or a related musculoskeletal disorder and at the time of these interviews, only around half of the women were still employed. Most of the women were over 40 years of age and married and RSI onset was 3-12 years prior to the interviews conducted in 1988. Almost 80% had left school before or at the age of 15. Of the 25 unemployed women, 20 had or were receiving workers compensation.

The women's experience of having RSI was interpreted as 3 stages:

1. Symptom evaluation
2. Illness action (what action they took i.e. help seeking)
3. Normalisation, when women 'normalised' changes due to illness by adjusting to work and home life.

In terms of evaluating and explaining their symptoms, 79% of the women commented that their work was fast and pressurised and attributed RSI to unreasonable work pressures and the nature of their work practices. Reid et al, (1991) argued that together with other contributory factors, their experiences represented the potent mix of technological change, machine and user. The women speculated that had they been disfigured, others might more readily have believed them. Those with surgical scars wore them as a 'red badge of courage' to prove

their suffering (Reid et al, 1991). Furthermore, these authors highlighted the adversarial nature of consultations because of doctors who did not believe in RSI, negative stereotyping of sufferers as well as doctors being nominated by the company or insurers in legal claims (Reid et al, 1991).

Despite this study's comprehensive treatment of the women's experiences, it is limited in its lack of inclusion of the male perspective of having RSI, and the perspective of younger females, since the sample consisted mainly of women over 40 and with a low level of education. One positive aspect of their work was that their samples were recruited from non - clinical settings, namely through work.

The other main research on the RSI experience was conducted in the UK by Arskey, (1994) who studied the social aspects of the RSI syndrome through conducting semi-structured interviews with nine RSI specialists, three GPs and eleven organisers of RSI support groups, most of whom were sufferers. Interviews focused mainly on the doctor-patient dimensions of RSI and usually lasted 90 minutes. Arskey, (1994) also had many informal conversational interviews with RSI sufferers and served on the management committee of the RSI Association. Arskey supplemented this work with a self administered postal questionnaire to 296 members of 3 RSI support groups. This aimed to gather standardised data on personal, medical and work biographies and respondents' dealings with medical practitioners. There was a 25% response rate and all except two respondents were females. The age covered in the sample ranged from under 19-late 50s with educational levels ranging from none to higher degree level, which is consistent with the current study. Arskey also reviewed the type of information which was disseminated about RSI. Overall, Arskey's aim was to study the social construction of RSI rather than the RSI experience per se.

Calnan et al, (2005) conducted qualitative interviews with 47 people with upper limb disorders to investigate how they evaluated their health care. These interviews were part of a larger quantitative study to evaluate health care use. They used a similar approach to Reid et al, (1991) but only studied the first phase of the illness career. Their findings suggested that pain relief was sufferers' main aim over diagnosis or other information.

Since there are very few studies of RSI, it is worth mentioning some general studies which have helped our understanding. For example, Bammer and Blignault, (1988) reviewed the consequences of developing occupational overuse syndrome (OOS) and found these to be chronic pain, disability, anxiety, depression, social withdrawal, family problems, damage to career prospects, and involvement in protracted legal action. The majority of sufferers did recover, at least to some extent. In another study, Dorland and Hattie, (1992) conducted a large scale telephone survey of Australian government workers from a psychological perspective to understand how people coped with having RSI. The study sample was exclusively female. Ironically although a small number of males had volunteered to participate in the research, they were excluded because of the desire to keep the population sample homogeneous. This was a significant omission since males are also affected by RSI and their experiences would have been useful to include.

## **5.9 What are the knowledge gaps on RSI illness experience?**

To date, few studies exist on the RSI illness experience and within those mainly the female perspective is represented. One explanation for this maybe that the studies were conducted in the aftermath of the Australian RSI epidemic of the late 1970s to mid 1980s when the stereotypical image of an RSI sufferer was a non professional woman, and often an immigrant, employed in low paid, monotonous and repetitive work (Reid et al, 1991). Little is known about whether the male illness experience of having RSI is the same or different from that of females. Therefore, this research will allow the experience of RSI to be understood from the perspective of both men and women, across a range of occupations, educational levels and age groups. This study includes well paid professionals such as web software developers, IT and business consultants, university lecturers, PhD students and a small number of self employed people.

## **5.10 Summary**

This chapter covered some of the main ways in which the complexity of illness has been conceptualised in the literature and discussed some of the more enduring

conceptualisations of illness experience which have emerged, such as Bury's (1982) biographical disruption and Charmaz's (1983) loss of self. Also covered were the unique difficulties experienced by individuals with medically unexplained symptoms such as CFS and FM who often experienced illness without objective signs of disease, in common with diffuse non-specific forms of RSI. This review has highlighted the paucity of studies of the experience of RSI. Notably only three groups/researchers have investigated the RSI experience; Reid et al, (1991)/Ewan et al, (1991); Arskey, (1994, 1998) and Calnan et al, (2005). Reid et al's (1991) seminal work remains a landmark study in this area. Hilary Arskey's work in the UK in the 1990s has also been influential in contributing to our understanding of the medical and social construction of RSI and how this impacts on people's experience of RSI. It was also noted that Reid et al's study focused exclusively on women. Arskey only interviewed a small number of RSI sufferers along with medical experts to obtain a more global picture of RSI. Calnan et al's study was limited in that it only focused on sufferers' health care experiences as part of a larger study. With so little research into the experience of RSI, large gaps in our knowledge remain about the complex nature of this experience, especially diffuse non specific RSI, indicating that further research into this area is warranted. This study aims to help address this gap by adding to the body of existing knowledge and providing a balance of male and female perspectives.

The following chapter provides background to the increasing role of the internet in health care research and delivery. Of particular relevance to this study are online support groups which enable people to share illness experiences in ways not previously possible. The opportunities this presents for both individuals needing support and researchers wishing to understand illness experiences are discussed.

## **6 Chapter 6: The internet, online support groups and health care research**

### **6.1 Introduction**

Having discussed our current knowledge and understanding of the personal experience of illness, this chapter now considers how the internet is changing the illness experience of the individual sufferer and health care delivery. The focus of this chapter is how the proliferation of disease-specific online support groups has impacted on the illness experience. The use of support groups by online subscribers is discussed together with implications for researchers wishing to use these as resources in health care research to understand illness experiences. As internet methodology was used in this study, this topic merits further consideration here.

### **6.2 Internet as a source of health related information and support**

Current estimates suggest there are over a billion global internet users lured by its rapid access to diverse information and its ability to connect people (Internet World Stats, 2007). The provision of medical information and support for those suffering with illness are two important features of the internet (Mayer and Till, 1996; Davison et al, 2000; Burnett and Buerkle, 2004; Barker, 2008). The emergence of over 70,000 health-related websites is testament to the importance of health related information on the internet (Cline and Haynes, 2001) with one recent article reporting there were over 12,000 websites and 3-5 million web pages related to the topic of pain alone (Polomano et al, 2007 in Waheed and de Gray, 2008). Moreover, internet usage patterns reveal over 111 million American adults sought online health-related information (Hamilton and Bowers, 2006). The internet provides both a 'virtual library' of medical information (Pitts, 2004) and access to different types of knowledge about health, illness and the body, both biomedical and non biomedical

(Broom and Tovey, 2008). Both types of knowledge are important to those with illness who frequently discuss such issues in the many thousands of online health related support groups which have emerged in the past decade (Davison et al, 2000; Lorig et al, 2002; Pitts, 2004). Online support groups offer a place/space where people can meet and interact with others with a similar medical condition to share their experiences, support self help and to obtain emotional support (Eysenbach et al, 2004; Davison et al, 2000). In 2004, Yahoo! Groups listed 25,000 electronic support groups related to health and wellness (Eysenbach et al, 2004). Online support groups provide one of the main channels through which people access online health related information (Cline and Haynes, 2001; Cotton and Gupta, 2004). Many of these online support groups archive their messages providing repositories of data on people's experiences of illness (Cudney et al, 2002; Davison et al, 2000). A further advantage of such archived data is that researcher influence is minimised since the archived e-mails pre-date any researcher involvement. Despite the advantages of online research, the analysis of archived e-mails remains an under-utilised option by qualitative researchers (Murray and Sixsmith, 2002).

### **6.3 Researching online support groups**

From a research perspective, the internet offers a novel way to better understand health related problems and has led to a proliferation of online health-related studies (Flicker et al, 2004). Topics already investigated online include breast cancer (Mayer and Till, 1996; Sharf, 1999); eating disorders (Winzelberg, 1997); addiction (King, 1994); sexual abuse (Finn and Lavitt, 1994); inflammatory bowel disease (Selwyn and Robson, 1998); parenting issues (Madge and O'Connor, 2003) and the experience of traumatic brain injuries (Nochi, 1998). More directly relevant to this study, the experience of contested illnesses has also been explored online. These include studies by Glenton, (2003) who analysed e-mails from a Norwegian back pain discussion list, Cudney et al, (2002) who used an online support group intervention for women with FMS; Barker, (2008) who analysed e-mails from a FM online support group for 12 months, Guise et al, (2007); and Dumit, (2006) who have both studied CFS. To date no similar study has been conducted on RSI using this novel methodology.

Such textual e-mail data has already been used to understand problems such as eating disorders, (Winzelberg, 1997), cancer (Klemm, 1998; Winzelberg et al, 2003), levels of medical misinformation on an RSI list (Culver et al, 1997), infertility (Illingworth, 2001), prosthesis use (Murray and Sixsmith, 1998) and online support for caregivers of Alzheimer's patients (Brennan et al, 1992).

The studies outlined above reveal benefits and issues for both patients and researchers. Through looking at these studies and others, we will discuss both of these perspectives in more detail in the body of this chapter.

## **6.4 Online support groups: users' perspectives**

### **6.4.1 The need for information in making meaning of illness**

Illness is potentially the most disruptive experience/event in a person's life, raising deep questions about the meaning of illness (Charmaz, 1983; Bury, 1988 in Bury and Anderson, 1988). In order to understand and make sense of illness, people usually search for health related information as an important aspect of coping (Davison et al, 2000). Such health related information has traditionally been obtained from health care professionals, the mass media and 'lay experts' with personal experience of the condition or of the health care system (Cotton and Gupta, 2004). Whilst all these sources of information are used, patients still consider doctors a main source of their medical information (Conrad, 1987). However, the literature suggests that patients are often dissatisfied with the level of detail of information provided by doctors leaving an information deficit (Conrad, 1990). In such cases, the onus is placed on the patient to find this supplementary information elsewhere (Lupton, 2003). For many patients the internet has helped fill this information void (Powell and Clarke, 2000). Attractions of the internet include the quantity and variety of information available which is continually updated, its immediacy as well as 24 hour a day availability (Cotton and Gupta, 2004). Broom, (2005) found that information and support on the internet had empowered men with prostate cancer to take control over their illness and released them from the social

constraints of male images of masculinity, such as being tough and unemotional (Broom, 2005).

#### **6.4.2 Features of electronic support groups**

Online support groups usually focus on a particular health problem (Broom, 2005). These disease-specific online groups are social networks which bring together those with a particular medical condition, facilitating communication and the exchange of knowledge and support (Powell et al, 2003; Eysenbach et al, 2004). More significantly, online support groups are a new social phenomenon enabling people to share their private illness experience with others (sometimes thousands) in the open and public forum of the internet (Barker, 2008). Such groups allow sufferers to meet and collectively make sense of their symptoms, to discuss their health concerns and find potential solutions and treatments (Barker, 2008). Being in contact with others can also be invaluable in helping reduce feelings of isolation (Cudney et al, 2002). Furthermore, the absence of face to face contact can make these groups more conducive to discussing sensitive or embarrassing problems (Murray and Sixsmith, 1998; Barker, 2008). Support groups exist in a wide range of styles and structures and evolve to meet group needs and goals (Davison et al, 2000). Over 60% of self help groups are professionally moderated (Davison et al, 2000). Internet support groups can exist as a mailing list, newsgroups, Usenet discussion forums or web based discussion boards (Eysenbach et al, 2004). Millions of people visit daily the tens of thousands of online support groups covering almost every illness to interact with others (Eysenbach et al, 2004; Fox and Fallows, 2003; Barker, 2008).

#### **6.4.3 How do members use online support groups?**

Individuals with illness or other health problems use online health related support groups in a variety of ways for different purposes as shown in Table 6.1.

However, common reasons are to gain insights about their illness from others whose opinions they value, to share their illness experiences and to exchange information and emotional support (King, 1996; Sharf, 1997). Davison et al, (2000)



described them as ‘venues for social comparison’ where people can learn from their collective experiences.

**Table 6.1: Ways people use online support groups**

- Information/advice about sickness, treatment, recovery, survival, impending death (Pitts, 2004; Sharf, 1997; Broom, 2005) allowing them to make informed choices. Also information can educate them e.g. learning medical jargon and create a more equal relationship with doctors
- Convenience of accessing from home, fast, rapid, virtual library of information (Broom, 2005)
- Support, opportunity to share experiences, affirmation, consolation, understanding, encouragement, camaraderie, collaboration, commiseration (Sharf, 1997; Sharf, 1999; Cline and Haynes, 2001; Barker, 2008; Eysenbach et al, 2004; Eysenbach and Till, 2001) and being able to vent feelings
- Feeling connected with others, gain reassurance they are not alone, reduced isolation (Cudney et al, 2002) and loneliness (Davison et al, 2000)
- Opportunity to lurk without the obligation to share their own experience (Davison et al, 2000; Broom, 2005)
- Provide a variety of perspectives on the same topic (Cotton and Gupta, 2004; Powell et al, 2003; Davison et al, 2000)
- Anonymity and less risk of being judged or of stigma if they have a sensitive or embarrassing condition (Murray and Sixsmith, 1998; Sharf, 1997; Broom, 2005; Cotton and Gupta, 2004; Davison et al, 2000). Reduced inhibition leading to greater intimacy and emotional expression (Broom, 2005)
- Validation of suffering (Asbring and Narvanen, 2003; Barker, 2008; Cline and Haynes, 2001)
- Promote medicalisation of contested illness and minimise self discrediting impact of contested illness e.g. FM, challenge medicine, define own symptoms (Barker, 2008;

Dumit, 2006)

- Liberated them from cultural images of masculinity (being strong and unemotive (Broom, 2005) and femininity e.g. physical beauty (Pitts, 2004)
- A way of providing some distance between the person and the disease and a forum separate from their daily lives (Broom, 2005)
- Empowerment (Cline and Haynes, 2001; Broom, 2005, Barker, 2008; Pitts, 2004)
- Provide a variety of perspectives on the same topic (including international) (Cotton and Gupta, 2004; Powell et al, 2003)
- Allow them to become 'experts' (Powell et al, 2003; Broom, 2005)
- Support for self help and patient choice (Powell et al, 2003)

The key benefits of the internet for patients are its convenience, anonymity and sheer volume of information available (Fox and Rainie, 2000; Powell et al, 2003; Powell and Clarke, 2000). In a study by Fox and Rainie, (2000), almost half of the respondents said they had discussed personal problems on the internet which they would not have discussed in face to face contact with others. In support groups patients acquired knowledge, skills, attitudes and awareness which helped them to make informed decisions about illness and its treatment and improved their quality of life (Sharf, 1997; Broom, 2005; Pitts, 2004). The provision of encouragement, empowerment, validation, reassurance, a sense of belonging and opportunities to forge close relationships are further reported benefits (Cline and Haynes, 2001; Mann and Stewart, 2000; Sullivan, 2003). Moreover, due to the removal of geographical barriers to access, such groups may comprise an international membership enabling users to draw on a wide range of health perspectives and experiences (Powell et al, 2003).

## **6.5 The need for social support during illness**

When people become ill, they can feel socially marginalised resulting in a need to compare experiences with others who have similar experiences (Davison et al, 2000). Social support from others has been shown to be an important factor in enabling those with illness to lead relatively normal lives despite adapting to and managing illness (Cudney et al, 2002; Davison et al, 2000). The provision of social support is said to buffer the negative impact of life events on health (Paykel, 1994 in Cudney et al, 2002 and Thomas, 1995 in Cudney et al, 2002). Social support can refer to different things such as attachment and intimacy, facilitating social integration, opportunity for nurturing behavior, reassurance of self worth, information and material assistance (Weiss, 1969 in Cudney et al, 2002).

Pitts, (2004) stated that the internet was an important place where people could express their personal experiences of sickness, healing, recovery, mourning and survival. In Pitts' (2004) study, women posted intimate aspects of their illness experience online including details of their mastectomies, disfigurement, hair loss, nausea, chemotherapy, physical weakness, immobilisation, fear, sleep loss and even impending death (Pitts, 2004). Pitts, (2004) argued that in dealing with some of the more unpleasant bodily aspects of sickness and treatment these women presented their bodies as they really were lived. Such candour is highly valuable to researchers wishing to better understand illness experiences as they really are lived.

Validating the illness experiences of people with medically contested conditions whose illness may be medically challenged, is a further important role of support groups (Asbring and Narvanen, 2003; Barker, 2008). The disparity between medical expertise and lay experience in contested illness may compel patients to become expert patients or advocates on their own behalf to find solutions that are more in agreement with their subjective experiences (Collins and Pinch, 2005 in Barker, 2008). Dumit, (2006) suggested that CFS sufferers used the internet to devise strategies to counter medical disparagement.

In sum, online support groups can also empower patients, validate their suffering, allow them to articulate their grievances and challenge medicine by promoting patient-led demand for medical recognition (medicalisation). Online support groups

also enable sufferers to define their symptoms in terms of organic disease and assign it disease status, a process termed illness reification (Barker, 2008). Moreover, having their illness experiences belittled by health professionals created a greater sense of illness solidarity (Barker, 2008). In online groups people could commiserate, collaborate, and support one another, share details and information about suffering, treatment options and medical encounters. Broom, (2005) found that online information and support positively affected the illness experience of patients by providing a sense of control and empowerment over their illness. Hardey, (1999) stated that the anonymity experienced on the internet enabled people to 'open up' and disclose sensitive information in a safe environment, commenting that support groups provided a haven for patients.

Online support groups are used for many purposes. They can provide rich and candid insights into illnesses because they focus on the genuine talk between people seeking help and therefore reveal what is significant and of concern to them.

In reviewing some of the literature on how support groups are used by participants, one can surmise that these very personal uses of support groups, particularly users' high expectations of emotional support and disclosure may explain why virtual support groups are often perceived by users to be a safe and private place (Mayer and Till, 1996; Peterson, 2003; Hardey, 1999). These perceptions of privacy and of the internet being a safe place have important implications for research and are discussed later in this chapter.

## **6.6 Researching the illness experience online**

Whilst internet technology provides unprecedented opportunities for those with illness to openly discuss their health problems with others in electronic support groups, this same technology permits researchers to collect and analyse this information which users may consider to be private (Peterson, 2003). In a small survey of patient advocacy groups and medical webmasters, Peterson, (2003) found that archived lists were regarded as protected space where members should be able to speak freely without fear that their messages were being used by anyone other than the intended audience (Peterson, 2003). She therefore recommended

that permission be sought from the individuals concerned or the web master prior to using archived information. Furthermore, Eysenbach and Till, (2001) discouraged researchers from lurking without permission, based on ample evidence of group participants who were hostile to researcher intrusion. These highlight some of the difficult issues for researchers wishing to conduct internet research.

### **6.6.1 Research considerations in using online support groups**

There are some unique and important issues to consider before using online support groups for research including:

- Characteristics/profiles of internet users
- Mis-information in support groups
- Presence of lurkers and lurking
- Nature of online communication and online communication style
- Online identity and the scope for deception
- Transcription issues
- Ethical considerations
- Ephemeral nature of data

#### *6.6.1.1 Who uses support groups?*

The internet is neither universally accessible nor universally used creating digital divisions between those with access to this technology and those who do not (Fox, 2005). Therefore people who use online support groups form a particular segment of the population since they must have access to appropriate computer technology, know how to use this technology, need experience in the social context of the internet media and be able to read and write (Wilson and Peterson, 2002). A further unique feature of support groups is that they are self selected (Davison et al, 2000). It is also claimed that women are more likely to use the internet for health information than men, with the highest use amongst those aged 30-64 (Powell and Clarke, 2000; Fox and Fallows, 2003; Fox and Rainie, 2000; Davison et al, 2000). A further consideration is that only certain socio demographic groups are represented in online samples. Furthermore it is argued that online support groups are used

more by marginalised groups such as those who have stigmatising or medically contested illnesses (Davison et al, 2000).

#### *6.6.1.2 Online lurkers and usage patterns*

A significant proportion of the online population may not directly contribute to the discussions but only read the messages of others, referred to as lurking (Davison et al, 2000). The percentage of lurkers is highly variable but the average is estimated at 45% (Nonnecke et al, 2006; van Uden-Kraan et al, 2008). Fox and Rainie, (2000) found that 60% of members of online communities posted messages whilst 40% lurked. From a research perspective this raises issues about what is more meaningful to record; the number of participants in the group (including those who lurk) or the number of people who actively participate in group discussions (Davison et al, 2000). Barker's (2008) study of usage patterns in a FM support group revealed that over a 12 month period, a total of 1814 e-mail postings were made by 249 participants in the group. However, during this period, 45.4% of people only posted one message; 22.5% of members posted 2 or 3 entries; 16% posted 4-10 messages; 8.4% posted 11-20 messages and 8% posted 20 or more messages. The most active participant contributed 145 posts over the year. The usage pattern showed that 19 individuals on the list (7%) contributed over 50% of the postings. Barker, (2008) commented that the most frequent participants were likely to be lurkers.

Users also varied their participation level; sometimes posting several messages whilst at other times posting nothing for months. Powell and Clarke, (2000) stated this was probably because people varied the use of support groups depending on which stage of their illness trajectory and health care they were at.

### **6.6.2 Online identity and deception**

#### *6.6.2.1 How identity is constructed online*

The internet offers a new medium for self presentation and identity construction (Chandler and Roberts-Young, 1998). This has generated considerable debate about how identity is constructed online through the presentation of self, since this

process occurs differently in disembodied online communities compared to face to face (Doring, 2002; Pitts, 2004). One principal difference between online and face to face communication is that the physical body is absent online and must therefore be created through the use of words, images and symbols (Pitts, 2004). It is argued that without the constraints of a physical body, individuals are free to construct their identity however they wish online, in terms of their age, gender, status, occupation, health or lifestyle. Numerous examples abound in the literature of identity transformations in e-mail and chat systems (Chandler and Roberts-Young, 1998).

In everyday life, people manage their self presentation through being selective about what information they reveal or conceal from others (Chandler, 1998). This entire process however is made easier online since cues are limited to written text (Jaffe et al, 1995 in Chandler, 1998). Moreover, the internet has challenged the traditional view of self as being a stable entity to a post modern view of self as comprising a number of multiple, independent and even contradictory identities which are fluid rather than static and change continually (Chandler and Roberts-Young, 1998; Markus and Wurf, 1987 in Doring, 2002).

It is suggested that the ease with which information on the internet can be updated mirrors the way a person's identity is continually being updated, making the internet an ideal venue for people to 're write their biography' (Chandler, 1998; Chandler and Roberts-Young, 1998; Hardey, 1999). However, despite the deliberate manipulation of identity by some people in synchronous communication systems and to a much lesser extent in e-mail systems, the consensus seems to be that in asynchronous communication people seem to be relatively honest about themselves (Bober, 2002; Chandler, 1998; Doring, 2002).

It is argued that online people can create virtual identities different to their off-line ones and can even create multiple identities (Turtle, 1995). This is made possible by the absence of the corporeal body in cyberspace, which then has to be represented through words, images, codes and symbols (Waskul et al, 2000 in Pitts, 2004).

A unique feature of online communication is that information can be shared with much larger audiences than previously possible with other forms of self-

presentation, creating networks which extend far beyond people's immediate social contacts (Chandler, 1998; Hardey, 1999). Through this process, people transform their private concerns into very public ones (Chandler and Roberts-Young, 1998). A further aspect of online communication is that people through their virtual selves interact with others whom they are unlikely to ever meet in person (Chandler and Roberts-Young, 1998). A further difference between online and face to face encounters is that the identities people create online are based on shared interests rather than traditional demographic markers of age, gender and ethnicity (Chandler and Roberts-Young, 1998). Rheingold, (1993) highlighted how highly successful communities could be established on the basis of shared interests.

### **6.6.3 Validity of online data**

There are important research implications of using online information since there is little opportunity to verify who is actually sitting typing the words on the computer, leading to the possibility of deception. Bober, (2002), for instance, stated that disembodiment online and uncertainty about user's identity raised questions about the validity of online data. The lack of visual cues such as facial expressions and body language provided researchers with fewer opportunities to verify the credibility of respondents than in face to face interviews (Bober, 2002). However, based on several months of observation of online behaviour, Bober, (2002) concluded that the majority of postings represented the truth, arguing online data had the same validity as face to face research (Bober, 2002). Pitts, (2005) in her study of 50 personal web sites of breast cancer survivors stated that in her data collection she did not apply criteria such as age, race, class, gender, or sexuality and was therefore unable to state anything about the off-line identities of the authors of the web sites. Whilst accepting that the online and off-line identities of these individuals might be different, Pitts (2005) conducted her research on the premise that the information on the websites was in some sense truthful. Taking Walther's (2000) view, Pitts considered overt misrepresentation on the internet to be inflated and stated that similar issues are faced in other forms of research such as survey responses (Pitts, 2005).



#### **6.6.4 Transcription issues**

In online support groups the e-mails exchanged within the support group are immediately electronically recorded, exactly as typed by the authors. This means data does not require transcription which contrasts markedly to spoken words in face to face or group interviews which are usually captured using a tape recorder, transcribed verbatim and then often returned to participants for checking. The advantage of computer mediated communication is that data remains faithful to the intentions of the author, since participants “type in their own data” (Herring, 1996), removing researcher bias and transcription errors such as punctuation, which can significantly change meaning. It is also means data is immediately available for analysis.

#### **6.6.5 Online communication and computer paralinguage**

An important concern about electronic communication is how this form of communication differs from face to face communication. Online communication occurs through the typing, reading, understanding and interpreting of messages on a computer screen. Most computer mediated communication is devoid of the visual and aural cues available in face to face conversation and in some senses is impoverished by this (Stewart and Williams, 2005). To compensate for the loss of visual and other cues, computer users have developed a ‘keyboard paralinguage’ to enhance meaning in this new medium (Murray and Sixsmith, 1998). Examples include ‘LOL’ (laugh out loud), FWIW (for what its worth), IMHO (in my humble opinion) etc and symbols such as emoticons to convey nuances in meaning such as sarcasm, a wink for tongue-in-cheek comments or capitals to denote shouting. These subtle additions help to bring computer based communication closer to spoken conversation than written text. An awareness of this paralinguage is essential for understanding meaning in online support group e-mails since it is a part of the online support group culture.

### **6.6.6 Ephemeral nature of online information**

Hardey, (1999) highlighted the ephemeral nature of internet sites and said data on the internet such as people's web or home pages may be temporarily or permanently removed. Researchers must therefore consider carefully how to capture and retain information from this ephemeral realm (Hardey, 1999). As stated earlier the ease with which information on the internet can be easily updated, made it an ideal venue for people to 're-write their biography' (Chandler, 1998; Chandler and Roberts-Young, 1998; Hardey, 1999). However this also meant that websites and support groups etc could disappear overnight which has implications for online research. Chandler, (1998) reported that some of the sites used for his research had since disappeared, highlighting one of the problems of online research.

### **6.6.7 Ethical considerations of internet research**

Online research presents researchers with new challenges in ensuring that the Belmont principles of autonomy, beneficence and justice, applicable to all research involving human subjects, are safeguarded online. As guidelines for ethical research are only beginning to emerge, much is left at the researcher's discretion and may be interpreted differently by the different disciplines (Walther, 2001 in Pitts, 2004). Frameworks reported by Frankel and Siang, (1999) and the Association of Internet Researchers (AoIR) (Ess and AoIR, 2002) offer researchers some guidance in resolving practical ethical issues.

## **6.7 Summary**

Internet use has dramatically increased over the past decade and this trend is likely to continue, particularly in the health care field (Barker, 2008; Powell et al, 2003; Cotton and Gupta, 2004). Online support groups are predicted to dramatically shape both the illness experience of individuals and the practice of medicine in the future (Barker, 2008). Furthermore, Fox and Rainie, (2000) suggest that as health management services become more limited, patients will be expected to assume

more responsibility for their own knowledge and choices about illness. This suggests that the importance of online support groups is likely to increase in health care making them an integral part of health care and therefore a good place to understand the way illness is experienced from the individual's perspective.

Whilst the internet is generally considered a public place, and that public behaviour, such as support group communication does not necessarily require informed consent, it is vital that ethical issues are carefully considered in the context of each particular online group.

Despite increasing online research into contested illnesses such as back pain (Glenton, 2003), CFS (Dumit, 2006; Guise et al, 2007) and FM (Cudney et al, 2002; Barker, 2008), to date, no similar research has been conducted on the RSI experience using this novel methodology. This study therefore seeks to address this knowledge gap. The next chapter discusses the theoretical underpinnings of the methodological approach and methods adopted in this study.

## **7 Chapter 7: Methodology and methods**

### **7.1 Introduction**

In this chapter, the following three broad areas are considered:

1. Methodological approaches to research
2. Methods of investigation appropriate to the chosen methodology
3. Ensuring the quality of the research.

In the first section we look at broad philosophies about knowledge, how it is constructed and perceived, and then relate that to the two main paradigms of research, qualitative and quantitative investigation. Once the stance for this study have been established and supported through the literature, the methods which are appropriate to achieving the aims in the study are discussed. Finally, issues of reliability and validity are discussed.

### **7.2 Methodological approaches to research**

Research represents the quest for knowledge or truth and is a diligent and systematic investigation to establish facts, concepts and insights to advance knowledge and to present these in a detailed, accurate manner. Ultimately research aims to add to the body of existing scientific knowledge but in a professional discipline such as health care, the knowledge generated is also expected to be of practical relevance to that profession, such as improved health or delivery of health care services (Morse and Field, 1995; Bowling, 2002).

However, ideas about how knowledge is produced vary depending on questions of ontology (our view of reality about the world) and epistemology (the theory of knowledge), such as what we can know and how we can know it (Crotty, 1998;

Bryman, 2004). These provide the theoretical underpinning for the research and are vital to consider.

### **7.2.1 Ontology**

Ontology is related to questions about the nature, structure and existence of reality (Crotty, 1998). Epistemology and ontology are closely related since the construction of meaning is also about the construction of meaningful reality (Crotty, 1998).

Realism for example is an ontological position which contends that realities exist outside the mind and is often associated with objectivism (an epistemological theory which contends that meaning exists in objects independently of any consciousness) (Crotty, 1998). However, realists accept that meaning in contrast cannot exist without engagement of the mind, and that a world of meaning can only be created through the conscious mind making sense of it (Crotty, 1998). Crotty, (1998) therefore argues that realism in ontology and constructionism in epistemology, are quite compatible.

Realists believe that multiple realities exist which can be approximated to through studying the phenomena under study (Hammersley, 1992; Patton, 2002). In accordance with this view, the ontological stance taken in this study is that whilst reality cannot be known, it can be approximated to through conducting qualitative research. Subtle realism is a perspective compatible with a constructionist epistemology (Crotty, 1998) and has been influential in this study. Seale, (1999) advocated the subtle realist approach because of its ability to combine the scientific aims of positivist research with post-scientific insights of social research. Seale, (1999) further argued that the subtle realist approach enabled researchers to maintain 'truth' as an ideal, whilst recognising that it was impossible to be certain that truth had been achieved in any given situation. At the same time, subtle realists do not assume that people's accounts are necessarily 'true or rational' in their own terms. Hammersley, (1992) identified the key element of subtle realism was the idea retained from naïve realism that research investigates independent, knowable phenomenon, but rejects the view that researchers have direct access to those phenomenon, assuming instead that all knowledge is based on assumption and purposes and is a human condition. Subtle realism also requires researchers to be more vigilant regarding the danger of errors than naïve realism (Hammersley,

1992). Subtle realism views people's beliefs and actions as constructions, including their accounts of the world 'but avoids the wholesale application of constructivism' to research practice (Seale, 1999:26).

### 7.2.2 Epistemology

Many different epistemological theories exist to explain how knowledge can be acquired. It is the differences between these different ways of 'knowing' which is of primary importance to the researcher, with choices about research methods being secondary to this (Guba and Lincoln, 1994; Schwandt, 2000).

The different epistemologies can be viewed as paradigms of inquiry (a pattern or model for conducting inquiry), each of which differs fundamentally in the axioms on which it is founded (Guba and Lincoln, 1982). Disciplined inquiry is based on the 'scientific paradigm' (rationalistic, positivist or quantitative research) and naturalistic inquiry (or anti positivist, interpretive or qualitative research) (Guba and Lincoln, 1982). In social science, the two main epistemologies used are objectivism (which adopts methods from the natural sciences to study social reality) and constructionism which asserts that human beings construct meanings and interpret the world through interacting with others in it (Crotty, 1998; Bryman, 2004). Positivism is a theoretical perspective closely allied to objectivism (Crotty, 1998) and interpretivism is the theoretical perspective which underlies constructionism (Crotty, 1998).

Some key differences between quantitative and qualitative research are provided in Table 7.1.

**Table 7.1: Differences between qualitative and quantitative research strategies**

<b>Characteristic</b>	<b>Quantitative research</b>	<b>Qualitative research</b>
<b>Ontological perspective:</b>	<ul style="list-style-type: none"> <li>• Reality is single, tangible, convergent, fragmentable</li> </ul>	<ul style="list-style-type: none"> <li>• Reality is multiple, intangible, divergent, holistic</li> </ul>
<b>Epistemology:</b>	<ul style="list-style-type: none"> <li>• Objectivism</li> </ul>	<ul style="list-style-type: none"> <li>• Constructionism</li> </ul>
<b>Theoretical perspective</b>	<ul style="list-style-type: none"> <li>• Positivism</li> </ul>	<ul style="list-style-type: none"> <li>• Interpretivism</li> </ul>

<b>Theory emphasis</b>	<ul style="list-style-type: none"> <li>• Theory testing based on prior principles</li> </ul>	<ul style="list-style-type: none"> <li>• Theory construction based on description, synthesis and abstraction.</li> </ul>
<b>Analytical approach</b>	<ul style="list-style-type: none"> <li>• Deductive - inferences used for prediction or prescription. sequential analysis</li> </ul>	<ul style="list-style-type: none"> <li>• Inductive approach, grounded in data, iterative process used to explore little known phenomenon</li> </ul>
<b>Data collection strategies used</b>	<ul style="list-style-type: none"> <li>• Large random samples used to statistically test relationships between variables</li> </ul>	<ul style="list-style-type: none"> <li>• Small samples, purposively selected to reveal detailed insights into the phenomenon under study</li> </ul>
<b>Research context</b>	<ul style="list-style-type: none"> <li>• Variables controlled in laboratory experiments</li> </ul>	<ul style="list-style-type: none"> <li>• Everyday life is examined in an uncontrolled natural setting</li> </ul>
<b>Aims of research</b>	<ul style="list-style-type: none"> <li>• Generate laws, theories, models or generalisations</li> </ul>	<ul style="list-style-type: none"> <li>• Describe accurately and understand the experience of the phenomenon studied.</li> </ul>
<b>Relation of values to inquiry</b>	<ul style="list-style-type: none"> <li>• Value free</li> </ul>	<ul style="list-style-type: none"> <li>• Value bound</li> </ul>
<b>Nature of truth statements</b>	<ul style="list-style-type: none"> <li>• Context free generalisations, nomothetic statements, focus on similarities</li> </ul>	<ul style="list-style-type: none"> <li>• Context bound hypotheses, idiographic statements, focus on differences</li> </ul>
<b>Data source</b>	<ul style="list-style-type: none"> <li>• Indirect studies focussing on relationships between variables.</li> </ul>	<ul style="list-style-type: none"> <li>• Human experiences form the primary data source</li> </ul>
<b>Generalisability</b>	<ul style="list-style-type: none"> <li>• Generalisability of statistical results to wider settings is a main aim of research</li> </ul>	<ul style="list-style-type: none"> <li>• Aim is to obtain rich data and in-depth understanding. Underlying theories maybe transferable to other settings</li> </ul>
<b>Inquirer/respondent relationship</b>	<ul style="list-style-type: none"> <li>• Independent relationship in which researcher observes objectively from a distance taking an “etic” or outsider perspective</li> </ul>	<ul style="list-style-type: none"> <li>• Inter related in which researcher is the research instrument taking an “emic” or insider perspective from the participant’s perspective.</li> </ul>

Table 7.1 Compiled from Morse and Field, (1995); Bryman; (2004); Marshall and Rossman, (1999); Crotty, (1998); Grbich, (1999); Guba and Lincoln, (1982)

Constructionism as a theory of knowing seems more appropriate for this study into the experience of RSI. It assumes that knowledge about human action and society depends on individuals and their relationships, experiences, context and time (Crotty, 1998). It further assumes that people's views and ideas are not predetermined but that knowledge is constructed in and out of human social

interaction and meaning. They believe reality is negotiated rather than discovered. Constructionists believe that the same things will appear differently to different individuals and acknowledge that multiple or conflicting versions of the same event or object can be true at the same time (Hammersely, 1992). This paradigm rejects the researcher as a neutral observer conducting impartial, fact based research, but acknowledges instead, that the researcher's ideas and personality influence the research process (Denzin and Lincoln, 2000). How people view an object or event and the meaning they ascribe to it, is central to interpretive constructionists (Rubin and Rubin, 2005).

Having considered these two main theories of knowledge, the perspective deemed most appropriate for the research aims in this study (to investigate the subjective experience of RSI sufferers), is constructionism using an interpretive theoretical perspective. A qualitative approach overall is considered congruent with the aims of this study which are to illuminate the experience of RSI from the individual's perspective.

Within qualitative research, different methods are available to access people's subjective views and the researcher must select the one most compatible with their research question.

### **7.3 Methods used in this study**

The principal data collection strategies used to access people's experiences in qualitative research are in-depth interviews, life stories, case studies, participation in the setting, direct observation, document analysis and study of artifacts (Marshall and Rossman, 1999; Denzin and Lincoln, 2000; Sandelowski, 2002). Qualitative inquiry typically involves more than one method to study the selected topic since multiple methods provide data triangulation (different ways of investigating it), which is actively encouraged in a multi-disciplinary field such as health care (Bowling, 2002).



### **7.3.1 Use of interviews in qualitative research**

Interviews are a well established and commonly used method (Sandelowski, 2002; Britten, 1995; Mays and Pope, 1996; Bryman, 2004) and have become the “gold standard” for data collection in health care research (Silverman, 2000). The primary aim of interviews is to generate data (Patton, 2002). They are a powerful and flexible research tool for understanding other human beings, allowing difficult topics to be investigated (Frey and Fontana, 2000; Britten, 1995). Interviews are considered a specialised form of conversation used to produce different kinds of interaction and to generate different types of knowledge (Kvale, 1996; Malterud, 2001). In qualitative research each interview is unique and the researcher tailors the questions to what each interviewee knows and is willing to share, making it both a science and an art (Malterud, 2001). Interviews can access people’s feelings, thoughts, intentions and motivations to provide insights into how they organize their world and give meaning to it (Patton, 2002). To aid the interview process, Rubin and Rubin, (2005) advocate making the interview an enjoyable experience as possible for participants, since empathy and good rapport encourage disclosure.

However, Sandelowski, (2002) cautioned that interviews should not be viewed as impartial data collection tools, since they are socially constructed and rely on the interaction between at least two people to generate an account. It is also emphasised that the interview involves mutual influence between interviewer/interviewee since it is a two-way process (Kvale, 1996; Rubin and Rubin, 2005). This means that the researcher must be aware of his or her own underlying cultural assumptions and consider how these influence the research process by reflecting on their own understanding and reactions (Rubin and Rubin, 2005). However, interviews have limitations as well as benefits which must be considered and are summarised in Table 7.2.

**Table 7.2: Benefits and limitations of interviews**

<b>Benefits of interviews</b>	<b>Limitations of interviews</b>
<ul style="list-style-type: none"><li>• They allow access to respondents' definitions and interpretations of the phenomenon studied</li><li>• They can help researchers understand the meanings people ascribe to everyday activities</li><li>• They can provide evocative illustrations of phenomena to help understanding</li><li>• Information is richer and more spontaneous than from surveys</li><li>• Allow researchers to probe issues, clarify or seek further explanations which may lead to more complex answers</li><li>• Their ability to penetrate so called "public accounts"</li><li>• People who cannot read or write can still be included in the research.</li><li>• Large quantities of information can be generated quickly</li></ul>	<ul style="list-style-type: none"><li>• Respondents may have selective recall</li><li>• All interviews are considered to be opportunities for "impression management"</li><li>• Researcher's high dependence on participant co-operation e.g. interviewees may withhold information the interviewer wishes to know or they may conceal the truth.</li><li>• What is said in interviews cannot be treated as a literal discussion but as accounts embedded in their circumstances of production.</li><li>• More expensive and time consuming to conduct and analyse compared to other methods</li><li>• The temptation to gather more information than is necessary</li><li>• The trade off between breadth and depth of subject matter covered.</li><li>• Interview outcome depends on researcher's ability to manage personal interaction, listening skills, ability to frame questions, probing and being able to elicit detailed narratives</li></ul>

Above Table 7.2 is based on Marshall and Rossman, (1999); HTA report, (2001); Rubin and Rubin, (2005); Kvale, (1996); Britten, (1995).

Having established the value of interviews for accessing and understanding people's subjective experiences, it is useful next to consider more specifically the various options available for conducting interviews.

### **7.3.2 Interviewing options available to researchers**

Although often presented as a single technique, interviews can take many different forms. The three principal types of interviews used in qualitative research are: structured, semi-structured and unstructured (Patton, 2002; Britten, 1995; Crabtree and Miller, 1992). Ultimately the type of interview selected will depend on the research aims (DiCicco-Bloom and Crabtree, 2006).

#### *7.3.2.1 Structured interviews*

Structured interviews are highly structured questionnaires administered in a standardised way to simplify subsequent coding and analysis of data, such as in epidemiological studies (DiCicco-Bloom and Crabtree, 2006; Bryman, 2004). They are appropriate if simple and brief statements are acceptable responses. However, they are unsuitable if more complex responses are required, if explanations are required from respondents or if the aim is to understand people's experiences, since these cases require a broader and deeper approach to interviews (Rubin and Rubin, 2005). Given the aim of this study is to understand the experience of people with RSI, survey type questionnaires are inappropriate for this study.

#### *7.3.2.2 Unstructured or open-ended interviews*

Unstructured interviews allow in-depth exploration of people's views and opinions on a small number of topics and are widely used to gain insights into respondents' personal experiences (Britten, 1995; DiCicco-Bloom and Crabtree, 2006). This interview method retains maximum flexibility by using only a very broad topic schedule to guide the interview, or in some cases, no questions are prepared in advance. Strengths of depth interviews include generating rich findings, providing insights into both subtle and explicit matters and highlighting absent data (Rubin and

Rubin, 2005). However, a major disadvantage of unstructured interviews is considered to be the large degree of variability which may exist between interviews, making it difficult for the researcher to manage, analyse and compare the data obtained.

#### *7.3.2.3 Semi-structured interviews*

Semi-structured interviews represent a middle ground between the previous two types of interview and are the most popular interview format used in qualitative research lasting from half an hour to several hours (DiCicco-Bloom and Crabtree, 2006). In semi-structured interviews, whilst some structure is retained in the interview process by having a list of pre set topics/questions to be covered during the interview, sufficient flexibility is available to allow researchers to pursue new and serendipitous issues and to change the question sequence (Rubin and Rubin, 2005).

In this study, semi-structured interviews were used to study RSI sufferers' experiences because of their proven utility for accessing subjective experiences combined with the balance they afford between structure and flexibility.

Having identified semi-structured interviews as the most appropriate method for this study, it is next useful to consider the different interview formats available. The principal decision concerns whether to use one-to-one interviews or a group format. The other decision relates to whether the interview will be conducted face to face or by other means, such as over the telephone or via the internet (Bryman, 2004). The choice selected will be determined by the research aims and by practical and logistical considerations (Bryman, 2004).

#### **7.3.3 Focus group interviews**

A key advantage of using focus groups over one to one interviews is the social environment they provide, allowing interactive processes to be accessed and observed. It was seen earlier that individuals do not make meaning of events and happenings in isolation, but rather meaning is constructed in social processes

through discussion and interaction with others. This makes focus groups highly appropriate for exploring and understanding people's experiences and concerns since they allow participants to ask questions, frames concepts and to direct the discussion in their own terms and language (Kitzinger and Barbour, 1999; Murphy et al, 1998). Furthermore, focus group interviews allow participants to both express their own views and respond to the views of others in the group (Kitzinger, 1994).

Other advantages include stimulating recall (or 'collective remembering') and opinion elaboration (Frey and Fontana, 1991). Additionally they can enable more reserved participants to discuss sensitive issues and allow people to clarify ideas (Kitzinger, 1994; Morgan, 1997). Interviewer influence is also minimised by being one amongst a group, compared to one to one interviews (Frey and Fontana, 1991) which is considered desirable. In focus groups where the emphasis is on group interaction, the realities are defined by the group members, and context and interpretations are based on group input (Frey and Fontana, 1991).

#### **7.3.4 Practical considerations in conducting focus group research**

At a practical level, conducting focus groups involves locating knowledgeable interviewees, finding a suitable research venue, deciding on the size and number of groups and considering how rapport will be built both with and between group participants. The researcher's role is often both the group facilitator and moderator (Krueger and Casey, 2000). As moderator, the researcher opens discussions, fosters rapport and establishes ground rules for participation. As facilitator, the researcher explains the research aims, process and procedures and attempts to keep discussions focused on the research question. For inexperienced researchers, Kitzinger and Barbour, (1999) advocate running pilot focus groups to gain familiarity with the method. They also warned researchers to expect uncomfortable, 'difficult moments' or painful exchanges between group participants, although this was not common (Kitzinger and Barbour, 1999).

At this point it is important to distinguish briefly between focus groups and group interviews. The difference is that in focus groups it is the interaction between participants that is important in understanding people's comments, whereas in group

interviews the focus is on turn taking with more importance placed on the communication between the researcher and each participant.

Table 7.3 lists some general features of focus groups. Few empirical studies exist in the literature to support any specific recommendations for running focus groups, but the procedures cited are usually based on the personal experiences of highly experienced researchers which others have used “as a rule of thumb” (Morgan, 1997; Bloor et al, 2001).

**Table 7.3: General features of the focus group method**

<ul style="list-style-type: none"> <li>• Aims to generate information/ data through group interactions (Kitzinger, 1995) which forms its “hallmark feature” (Morgan, 1997)</li> <li>• The group is usually specifically convened for discussion of a particular topic specified by the researcher, although existing groups may be used (Morgan, 1997; Kitzinger, 1994).</li> <li>• There is usually some “group homogeneity” or “common focus” in the discussion topic</li> <li>• A “nurturing” and “non threatening” environment” is considered important for enhanced personal disclosure (Morgan, 1997; Krueger, 1998; Kitzinger, 1994).</li> <li>• The group size recommended is typically small, with ideally around 6-8 participants (Krueger and Casey, 2000), 4-8 Kitzinger, (1995), 6-10 (Morgan, 1997) 6-10, (Bloor et al, 2001)</li> <li>• The recommended duration for face to face (FTF) focus groups is 1-2 hours (Krueger, 1998; Kitzinger, 1995; Stewart and Shamdasani, 1990) by which time data saturation should have occurred</li> <li>• The recommended number of groups to run for FTF groups is usually 3-5 groups in series (Morgan, 1997). A minimum of 3 is recommended and one group only is discouraged as this may only reflect group dynamics (Krueger and Casey, 2000).</li> <li>• During analysis findings are compared within and across groups for common themes as well as deviances (Morgan, 1997).</li> <li>• Moderator’s interaction with participants has an important influence on the research outcome (Sweet, 2001).</li> </ul>
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- The desirability of “acquaintanceship”, i.e. whether group participants should be strangers or be known to each other, is still debated (Stewart and Shamdasani, 1990; Kitzinger, 1995).

### **7.3.5 Influence of technological advances on data collection**

Research methods change over time. One example of this was the introduction of telephone interviews which provided a new and different way of conducting interviews and which has now become commonplace (Denscombe, 2003). In a similar way, the rapid expansion of internet technology has broadened options for conducting research (Denscombe, 2003; Mann and Stewart, 2000; Stewart and Williams, 2005). The ease of access to vast quantities of information, including health care information, and the availability of new social spaces for people to meet, has led to major changes in the way people think about their health and illness (Fox and Fallows, 2003). The internet enables people with illness to meet in online support groups to discuss and share their illness experiences and concerns. This in turn has offered researchers new and additional ways to conduct health care research including accessing people's illness experiences. Online support groups were discussed in chapter 6.

### **7.3.6 Modes of conducting online interviews**

Online interviews can be facilitated in different ways from e-mail exchanges to bulletin boards, chat rooms or messaging services such as those offered by Yahoo! or MSN Messenger (Bloor et al, 2001; Denscombe, 2003; Mann and Stewart, 2000; Jones, 1999). Specialist conferencing software can also be used, but this is expensive and technically complex, although it offers greater privacy and is safer in terms of confidentiality. For example, quotes cannot be Google searched such as on the open internet to trace the original author (Stewart and Williams, 2005).

#### *7.3.6.1 Online or 'virtual' focus groups*

Online focus groups have already been used in health care research (Murray, 1997; Kenny, 2005). Bloor et al, (2001) stated that online focus groups offered several advantages over conventional focus groups. They are more economical (since travel costs and audio transcription costs are removed), there are no time constraints (except resources), allowing groups to run for weeks and months, the size of the groups can accommodate more people than traditional focus groups, geographically dispersed individuals can participate and interviewees may prefer to participate in interviews from home, at their own convenience rather than attending face to face meetings (Bloor et al, 2001). A major disadvantage of focus groups however is that internet use is still relatively exclusive, although demographic disparities have diminished (Bloor et al, 2001). An important implication of this is that online focus groups maybe most appropriate for studying groups of people who are already familiar with e-mail communication (Bloor et al, 2001). Furthermore, it is argued that since focus groups aim to access group norms and understandings, there may be advantages in recruiting participants from pre-existing social groups (Bloor et al, 2001). Bloor et al, assert that "online focus groups are not a new method but rather a new dimension of an established method, offering new opportunities for focus group research" (Bloor et al, 2001:86).

The next section discusses the increasing use of the internet in health care research as an alternative venue for accessing and studying illness experiences (Davison and Pennebaker, 1997).

### **7.4 The impact of the internet on health care**

Global estimates indicate over 111 million people searched for health care information on the internet in 2004 (Hamilton and Bowers, 2006). A 2007 report by Pew Internet and American Life Project (a non profit organisation which examines the social impact of the internet) estimated 34 million people in America were living with a disability or chronic disease, of whom half searched for online health-related information. Cline and Haynes, (2001) reported there were over 70,000 health related websites, whilst Waheed and de Gray, (2008) in the British Pain Society



newsletter, reported that over 12,000 websites and several million web pages were currently devoted to the topic of pain alone (Polomano et al, 2007). Cotton and Gupta, (2004) stated that support groups formed one of the main channels through which people accessed health care information. This information confirms that the provision of medical information via the internet is becoming a mainstream activity. Allied to this, the number of internet support groups, which connect people in social communities providing a forum for people to exchange information, share experiences and gain emotional support, is growing (Mayer and Till, 1996; Sharf, 1997; Winzelberg, 1997; Eysenbach and Till, 2001). Such online groups can enable researchers to access information which would otherwise be difficult.

#### **7.4.1 Accessing illness experiences in online support groups**

People usually discuss their illness experiences informally with family and friends (Cotton and Gupta, 2004). This can make gaining access to such illness accounts problematic for researchers (Davison and Pennebaker, 1997). Online support groups offer researchers a new place to access such informal talk to help better understand people's illness experiences (Eysenbach and Till, 2001). Online support groups are usually disease-specific, enabling those with a common illness to meet and discuss their experiences, gain understanding of their illness and find solutions to their concerns (Sharf, 1997; Winzelberg et al, 2003).

Information exchanged in internet support groups usually involves participants compiling and posting e-mail messages to a central list which can be read by all other subscribers to that list (Suler, 2000; Forkner-Dunn, 2003; Barker, 2008). These postings between members of the support group may be stored in archives for the benefit of later users (Sixsmith and Murray, 2001; Eysenbach and Till, 2001; Forkner-Dunn, 2003). This rich data repository can provide researchers with opportunities to learn about and better understand sufferers' experiences (Davison and Pennebaker, 1997).

The information generated from online research is believed to be comparable to face to face groups. For example Lieberman and Russo (2001-2) compared face to face and internet based self help groups and found members from both types of

support groups behaved similarly and had similar expectations of their involvement. Similar findings are reported for other support groups e.g. Glenton, (2003) found similar results in an online back pain discussion group. This makes them ideal places to access such common illness related issues.

However, online support groups need to be approached with caution since they are often established with the aim of providing information and comfort for those who are ill, distressed or vulnerable (Sharf 1999) requiring ethical issues to be considered carefully. Despite the ethical issues, many online research studies have been conducted, with support groups being a popular source of data. Table 7.4 provides examples of online health-related research and methods used.

**Table 7.4: Examples of online health- related research and methods used.**

Author	Group/health topic studied	Internet method/s used
Brennan et al, (1992)	Caregivers of Alzheimer's disease	E-mail postings
Finn and Lavitt, (1994)	Experience of sexual abuse survivors	> 1100 postings from 6 online groups
Mayer and Till, (1996)	Breast cancer	E-mail postings
Murray, (1997)	Global views of health professionals	Asynchronous focus groups
Winzelberg, (1997)	Eating disorders (anorexia)	306 e-mail postings over 3 months
Culver, (1997)	Assessment of accuracy of medical information in RSI support group	1,658 e-mail postings covering 5 month period
Selwyn and Robson, (1998)	Employment experiences of inflammatory bowel disease sufferers	Single asynchronous online focus group with 57 people and FTF interviews
Nochi, (1998)	Traumatic brain injury	Interviews and e-mail postings from a list with 270 members over 11 months
Murray and Sixsmith, (1998)	Prosthesis users	E-mail interviews conducted over 2-6 month period
Klemm, (1998)	Colorectal cancer	300 e-mails from support group with 125 members
Stewart et al, (1998)	Cross cultural study assessing internet utility for health promotion	Real time online focus groups over 4 research sites in Australia and Malaysia
White and Dorman, (2000)	Alzheimer's disease caregivers	Analysed themes in 532 e-mail postings
Hardey, (2002)	Illness accounts on internet personal home pages	98 e-mail questionnaires sent
Winzelberg et al, (2003)	Breast cancer	E-mail postings to support group
Glenton, (2003)	Back pain	Norwegian back pain discussion list e-mails and in-depth interviews
Madge and O'Connor, (2003)	Parenting issues	Focus group using conferencing software and online discussion list
Kenny, (2005)	Reasons for nurses taking a	Single asynchronous online focus group

	conversion programme	with 38 participants for 2 months
Guise et al, (2007)	Chronic fatigue syndrome	Combined methods using 49 people from internet support groups (38 chatline and 11 one to one online interviews) and 7 FTF interviews
Dumit, (2006)	CFS	Analysed e-mail postings
Bennett et al, (2007)	Fibromyalgia	Internet survey amongst 2,596 people with fibromyalgia
Barker, (2008)	Medicalisation of FM	Read support group e-mails for 1 year

In contemplating the use of online focus groups, it is necessary to consider both their potential advantages and disadvantages, which are provided in Table 7.5

**Table 7.5: Advantages and disadvantages of online focus groups**

Advantages of online focus groups	Disadvantages of online focus groups
<ul style="list-style-type: none"> <li>• Embarrassing topics can be covered as participants are hidden from view</li> <li>• Participants have more time to reflect and can provide a more considered response</li> <li>• Geographically dispersed groups can be brought together at relatively low cost</li> <li>• Global perspectives can be gained rapidly facilitating cross cultural studies</li> <li>• Significantly larger numbers can participate, enabling a broader perspective to be gained (Selwyn and Robson's (1998) study involved 57 people for two months).</li> <li>• Flexibility of asynchronous groups allow participants to respond at their own convenience</li> <li>• Transcription time, costs and errors are eliminated as a verbatim record of the communication is captured, thereby removing transcription errors and data is available immediately for analysis. (Mann and Stewart, 2000; Chen and Hinton, 1999)</li> <li>• Savings in time, effort, travel, cost or need to find a replacement care giver, since participants can access the site from home</li> <li>• Potentially easier to involve 'difficult to access groups', such as, parents, busy professionals (Mann and Stewart, 2000; Madge and O'Connor, 2003; Murray, 1997) or the</li> </ul>	<ul style="list-style-type: none"> <li>• Group interaction, dynamics and spontaneity may be reduced when compared to FTF groups due to the longer time gap between the question being asked and the response (Denscombe, 2003).</li> <li>• The lack of visual cues (unless a video link is used) places a total reliance on the written word denying the researcher additional cues from behavioral gestures and facial expressions.</li> <li>• Greater effort is required from the researcher and participants to make everything explicit in efforts to reduce misunderstandings.</li> <li>• There is a greater risk of information disclosure by participants (Denscombe, 2003).</li> </ul>

<p>immobile</p> <ul style="list-style-type: none"> <li>• Effects of age, gender, disability and culture of both interviewer and interviewee maybe reduced enabling the merit of what is said to carry greater weight than other factors</li> <li>• The extended period of interaction from days to years may enable more in-depth and different perspectives to be gained than 1-2 hour FTF (Sweet, 2001).</li> </ul>	
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Above Table 7.5 compiled from Bloor et al, 2001; Murray, 1997; Denscombe, 2003; Mann and Stewart, 2000; Madge and O'Connor, 2003; Chen and Hinton, 1999; Sweet, 2001

#### 7.4.1.1 *Practical considerations when interviewing*

Bryman, (2004:23) stated that “all research was a coming together of the ideal and the feasible” meaning researchers must consider carefully the practical issues as well as the theoretical ones.

Some practical considerations in interviewing are:

- Selecting participants with relevant experience and knowledge about the research topic and who can and are willing to convey this to the researcher (Rubin and Rubin, 2005)
- Accessing contradictory views and nuanced understandings of participants by including a wide range of perspectives to illuminate different aspects of the topic (Rubin and Rubin, 2005)
- The researcher must clearly explain interview aims and process and ensure that questions are appropriate for obtaining the information needed (Patton, 2002).
- The language used in interviews must be appropriate for the participants and take into account participant diversity (Britten, 1995).

- Participants must be made to feel relaxed and comfortable as possible to enhance disclosure in focus groups (Kitzinger, 1994; Morgan, 1997; Madge and O'Connor, 2003).
- The researcher must anticipate factors which may occur during interviews such as interruptions, competing distractions, participants too frightened to speak, awkward questions or topic jumping (Morse and Field, 1995).
- Researchers must anticipate and address problems such as interviewees monopolizing time in the focus group interview (Barbour and Kitzinger, 1999)
- The interview process should begin with questions which participants can answer easily to help put them at ease, and then progress to the more difficult questions (Patton, 2002).

#### **7.4.2 Importance of data triangulation**

While interviews are very valuable research tools, no method can perfectly capture all aspects of a phenomenon (Bowling, 2002). Trustworthiness in research can be enhanced by studying the topic from different perspectives (Lincoln and Guba, 1985; Denzin and Lincoln, 2000), termed triangulation. Triangulation enables a more complete picture of a phenomenon to be gained and stimulates reflexive analysis (Murphy et al, 1998). Documentary analysis is a qualitative method that complements interview data well, providing another perspective to better understand the phenomenon's complexity (Marshall and Rossman, 1999). Given the aim of this study was to gain an in-depth understanding of the experience of RSI, data triangulation was deemed beneficial and was therefore a feature of the design involving the documentary analysis of archived e-mail posts combined with online asynchronous focus groups.

Documents used in documentary analysis must be analysed and interpreted to give meaning to them so it is useful next to consider the options available for this process.

## **7.5 Documentary analysis of archived data**

Studying and understanding documentary sources and archives can provide rich sources of information from which much can be learned (Patton, 2002). Marshall and Rossman, (1999) stated that archived data, (records of a society, community or organisation), can usefully supplement other qualitative methods. Documents produced either in everyday activities or specifically for research purposes can provide insights into the values and beliefs of participants in a particular group or setting (Marshall and Rossman, 1999). Moreover, archived data is considered an unobtrusive means of data collection and relatively straight forward if it is pre existing (Marshall and Rossman, 1999). However, despite its many advantages, Murphy et al, (1998) commented that documentary analysis remained under-utilised. The major disadvantages of documentary analysis are that as a stand alone method it can provide a distorted view of the phenomenon and there may be important ethical implications.

Documents are often analysed using content analysis which can be used to analyse any form of written communication from newspapers to e-mail messages (Robson, 1993; Marshall and Rossman, 1999). Although content analysis was originally associated with counting how many times a specific term or word was mentioned in text as an objective way of obtaining a quantitative description of communication content, it has gradually evolved into a method for describing and interpreting records of a society or social group (Marshall and Rossman, 1999). Another popular approach for analysing e-mail communication is thematic analysis where patterns in the data are used to develop themes to capture and reflect the essence of the data to help construct an overall picture of the topic (Boyatzis, 1998). There are different ways of analysing research data to give it meaning and are considered next.

### **7.5.1 Data analysis**

From analysing data, the researcher produces one version of reality from the myriad of possibilities which exist. Whilst analysis refers broadly to the process of reducing data into its constituent elements and structure, in practice there are many different

ways of doing this (Dey, 1993; Tesch, 1990). However, most analysis involves considering how the data will be managed, stored and retrieved; what basic unit of analysis will be used (e.g. in focus groups the whole group is the basic unit rather than the individuals within the group), ensuring data will be coded in a consistent manner, and how recurrent patterns in the data will be discerned, collected together and coded. Consideration is also given to how the data assigned to each code will be subsequently analysed to identify its constituent dimensions, how the coding system will be refined to ensure the categories are mutually exclusive (i.e. do not overlap), how deviant cases that fall outside the coding structure will be explained and treated, how the data will be conceptualised overall and how findings will be organised and presented (Patton, 2002; Murphy et al 1998; Gibbs 2002).

### **7.5.2 Importance of reporting research context**

Since all qualitative research is context bound (Denzin and Lincoln, 2000), it is important for the researcher to report the circumstances under which the data was collected to provide a definition of the setting (Altheide and Johnson, 1994). This includes reporting information on the background, physical (virtual) setting, participants, activities, social rules, importance and order of events as well as members' perspectives and meanings (Altheide and Johnson, 1994). Describing the research context is also important because generalisability is often a problematic issue in qualitative research. In the case of focus groups, the researcher must also provide information relating to the group dynamics and interaction between group members as well as reporting substantive research findings (Webb and Kevern, 2001; Cattarall and Maclaren, 1997).

### **7.5.3 Computer-assisted data analysis**

As stated earlier, qualitative research generates large volumes of data which must be managed so that it can be systematically reduced to uncover and understand important aspects of the phenomenon (Patton, 2002). The use of computer software to store, code and manipulate data has become common practice (Tesch, 1990; Murphy et al, 1998; Gibbs, 2002; Bazeley and Richards, 2000; Patton, 2002).



However, it is important to note that whilst the computer helps in performing the clerical tasks of data management and retrieval, it is the researcher who carries out the analytical tasks of deciding what is coded, what constitutes a theme, the names allocated to themes, the significance assigned to data and in abstracting and conceptualising findings (Mason, 2002; Patton, 2002; Gibbs, 2002). Moreover, Boyatzis, (1998) stated that whilst computers can help locate manifest codes (explicit meanings) in the data, they could not detect latent codes, (implicit meanings embedded in text), and both were essential for gaining insights.

Computer use also affords more opportunities to organise the data in different ways and to re-examine the data once themes have been discerned. Several software programmes exist to facilitate data analysis such as Atlas Ti, Nudist, Ethnograph, Nvivo (Richards and Richards, 1994). Most offer similar facilities and the choice is usually one of personal preference (Bloor et al, 2001). In this study, Nvivo software was used to help manage and manipulate data.

## **7.6 Quality in qualitative research**

Validity, reliability and generalisability are the principal criteria used to assess the quality of quantitative research which are based on the realist assumption that reality exists and can be measured objectively. However, quality in qualitative research is altogether a more elusive concept and is difficult to define and achieve because it cannot be carried out according to pre-specified methodological rules like positivist approach (Seale, 1999). In addition, the issue of whether and how qualitative research should be evaluated remains highly debated (Murphy et al, 1998). The key issue is whether existing criteria can and should be used to evaluate post positivist research or if separate criteria for qualitative research should be developed (Mays and Pope, 1996).

### **7.6.1 Debates regarding criteria for evaluating qualitative research**

Currently there is no consensus regarding which criteria should be used to evaluate the quality of qualitative research. General advice offered by Seale, (1999) was that researchers should provide sufficient detail of their research processes to allow

readers to judge the quality of the research, and that they should always strive to maintain a self-critical approach to their research.

#### *7.6.1.1 Position 1: Extreme relativist position*

Extreme relativists argue that qualitative research is a completely different paradigm to quantitative research, based on fundamentally different underlying assumptions, and believe qualitative research cannot, and should not, be judged according to existing positivist criteria. However, Murphy et al, (1998) and Morse and Field, (1995) argued that such an extreme relativist position was unhelpful in applied health care research, since the rejection of validity and reliability might be construed as a rejection of rigour and render qualitative studies unscientific.

#### *7.6.1.2 Position 2: The relativists call for distinct evaluative criteria*

Relativists or anti realists advocate that the principles underlying the concepts of validity, reliability and generalisability used in positivist research be retained, but be replaced by parallel concepts which are more appropriate for qualitative research. Strauss and Corbin, (1998) for example argued that whilst the canons of good science had value, they needed redefining to take account of the complex and social nature of qualitative research (Pope et al, 2000). Relativists reject naïve realism, the belief that there is a single, social reality or truth which exists independently of the researcher and research process, believing instead that multiple perspectives of the world are created and constructed in the research process (Mays and Pope, 2000).

#### *7.6.1.3 Position 3: Positivist criteria be retained*

Some researchers continue to support the relevance and application of positivist criteria to qualitative research (Lincoln and Guba, 1985; Morse, 1999; Whitemore et al, 2001). Included in this group are subtle realists who believe that all research is inherently subjective and that using different methods produces different perspectives. However, unlike anti realists, subtle realists believe that an underlying reality does exist which can be known through studying it (Seale, 1999; Pope and

Mays, 2006). Seale, (1999) stated that central to subtle realism is the notion of agreed community standards for judging research credibility and relevance. In this study the subtle realist approach has been influential in gaining insights into RSI sufferers' experiences.

### **7.6.2 Criteria for evaluating qualitative research**

The need to assess the quality of qualitative research has led to a proliferation of evaluative schemes (Mays and Pope, 2000). These include schemes proposed by Patton, 2002; Mays and Pope, 1995, 2000; Malterud, 2001; Sparks, 2000 and Murphy et al, 1998.

One commonly used set of criteria used to evaluate the worth of a study are those proposed by Lincoln and Guba, (1985) based on the overall concept of 'trustworthiness'. Trustworthiness is based on establishing four main evaluative criteria; credibility (the truth of findings), transferability (applicability of findings to other contexts), dependability (producing consistent and replicable findings) and confirmability (extent of researcher influence). The criteria for establishing trustworthiness proposed by Lincoln and Guba (1985) and the techniques for achieving these are presented in Table 7.6.

**Table 7.6: Guba and Lincoln's (1985) criteria and techniques for establishing trustworthiness in qualitative data**

<b>Evaluative criteria</b>	<b>Credibility</b>	<b>Transferability</b>	<b>Dependability</b>	<b>Confirmability</b>
How the evaluative criteria are defined and interpreted	A truthful representation of the phenomenon based on the data to produce believable findings. This assesses whether the respondents' reality is represented appropriately	Generate findings which extend beyond the immediate study to other contexts	Produce findings which are consistent and replicable and refers to stability of findings	To generate findings which are neutral from researcher bias or motivations
Techniques for incorporating or safeguarding trustworthiness criteria	<ul style="list-style-type: none"> <li>• Prolonged engagement</li> <li>• Triangulation</li> <li>• Peer debriefing</li> <li>• Negative case analysis</li> <li>• Member checking</li> </ul>	<p>Use of theoretical or purposive sampling to maximise range of information collected</p> <p>Thick description to impart a vicarious experience of the phenomenon and enable judgments to be made about its applicability to other settings</p>	<p>Use of triangulation</p> <p>Dependability audit explaining all methodological steps and decisions</p>	<p>Triangulation</p> <p>Practicing reflexivity to expose researcher's underlying epistemological assumptions,</p> <p>Peer debriefing</p> <p>Confirmability audit to demonstrate that each finding can be traced back through the analysis to the original data</p> <p>Interpretations are reasonable and meaningful</p>
Analogous rationalist criteria	Internal validity	Generalisability	Reliability	Objectivity

Guba and Lincoln, (1982) suggested researchers should incorporate these criteria into research to maximise trustworthiness of data and to provide greater confidence to others that the material presented is of value and merits attention (Guba and Lincoln, 1985).

Some key ways in which the creditability of analysis can be maximised include: providing a truthful account of data, a prolonged engagement with the data, triangulation, peer debriefing, negative case analysis and member checks. The ways in which these have been incorporated into this study are summarised in table 7.7 below.

**Table 7.7: How quality has been incorporated into this study**

<b>Quality standard</b>	<b>How this has been implemented in this study</b>
Triangulation	In this study, a triangulation involving two different sources of qualitative data (Patton, 2002) was used in which archived e-mails and electronic focus groups were used to illuminate different aspects of sufferers' RSI experiences.
Represent the findings from the participants' perspective	The aim of this study was to understand the experience of RSI from the sufferer's perspective.
Flexible research design to gain topic depth and to capitalise on serendipitous findings	A semi-structured interview approach using a broad topic schedule to provide some structure whilst retaining sufficient scope to pursue unanticipated ideas or issues was used.
Maximum variability in study sample to explore fully all dimensions of the phenomenon	Study included people of different ages, both sexes, from varied occupations, students, and those sick, people with different types and at different stages of RSI. Triangulation of methods helped increase coverage of this variability.
Actively seek those who can help illuminate understanding	Purposeful sampling used. Repeated requests made for male participants to ensure balanced view obtained.
Provide sufficient evidence and detail of research processes to support findings and enable readers to judge the quality for themselves and assess applicability of data to other research contexts and groups	Thick description of sufferers' perspective as seen by them. Clear explanations provided of procedures, processes and rationale for decisions made. Log kept of all coding procedures and development of codes and themes, representative illustrative quotes used to support findings.
Ethical procedures sensitively addressed and high standards maintained	Careful consideration given to ethical issues, experts consulted, direct quotes were not used from the e-mail analysis as permission had not been obtained, but were used in the focus group data where informed consent had been obtained.
Awareness of researcher influence on the research process	Reflective practices were incorporated throughout research. Decision making was examined and recorded regarding what was done and why. Peers were involved in the review of analysis and interpretations.

Demonstrate quality of findings, produce a plausible and coherent account and consider relevance and transferability of findings	Rich description of sufferers' experiences of RSI provided. Log kept of developing thoughts as these changed including impressions, decisions made, alternative explanations considered, basis for data reduction. Inconsistencies in data analysis sought and efforts made to explain these. Member validation checks used, peer reviews incorporated in research. Accurate description of sample, recruitment processes, groups and context provided.
Researcher credibility	Meticulous records of analytical processes kept and research process made explicit, reflective practice used throughout all stages of study, transparent audit trail left.
Sufficiently prolonged engagement with data to gain enough familiarity with settings to draw conclusions, establish rapport, minimise researcher effect	E-mails covered for a six month period, online focus groups run for 10 days each allowing sufficient time to build rapport, trust, minimise researcher effect, and provided an extended immersion with the participants and data.

## 7.7 Summary of methodological discussion

This chapter provided the theoretical underpinnings for this study and emphasised how this influenced the choice of methods selected to answer the research question. In this study the qualitative paradigm was considered the most appropriate strategy for accessing and understanding the subjective experience of RSI. Purposeful sampling was selected as the data collection strategy to illuminate the phenomenon under study. It highlighted that online support groups provide new ways of accessing people's illness experiences and have already been successfully used in health care research. The format chosen for collecting interview data was online focus groups. A triangulation of methods was used to obtain a more comprehensive understanding of the RSI experience, by undertaking documentary analysis of archived e-mail posts and online focus groups and then integrating the findings. The chapter concluded with a discussion of the nature of quality and how this could be evaluated in qualitative research and how quality and rigour were incorporated in this study. Table 7.8 provides a summary of the theoretical underpinning of this study to investigate the experiences of people with RSI and the methods selected.

**Table 7.8: Theoretical underpinnings of this study and methods selected to investigate sufferers' experiences of RSI.**

<b>Theoretical issue</b>	<b>Approach taken in this study</b>
Research aim	To understand the experience of RSI from the sufferers' perspective
Ontological stance	Subtle or critical realism
Epistemological stance	Constructionist
Theoretical perspective	Informed by interpretivism
Methodological approach	Qualitative paradigm – gaining insights into experience via non-numerical data (web postings).
(Online) Methods used	Documentary analysis of archived e-mails and asynchronous online focus group interviews
Analytical approach	Deductive (e-mails) then inductive (Thematic analysis of focus groups and returning to emails)
Data collection strategy	Purposive sampling (maximum variation) pre-existing data and data generated by focus groups

## **7.8 Outline of the practical phases of this research study**

The next section begins the practical phase of this research study and will cover the research methods used, data analysis and presentation of findings and discussion.

### **7.8.1 Research phases of this study**

In the following chapters the methods, findings and discussions are presented for this study.

Chapter 8 covers the e-mail analysis study including

- Methods
- Findings
- Discussion

Chapter 9 covers the online focus group study including

- Methods
- Findings
- Discussion

Chapter 10 covers the issues arising from integrating the analysis of both research phases.

Chapter 11 presents the conclusions and discusses the contributions of the study, identifies areas for further research and covers the research limitations.



## **8 Chapter 8: Phase 1 of research: Documentary analysis of support group e-mail posts**

### **8.1 Introduction**

An integral part of writing up the research process involves providing sufficient information to enable readers to evaluate the research for themselves (Seale, 1999; Patton, 2002). This chapter therefore aims to provide a full and accurate account of the research procedures and processes involved in conducting this study and the findings. It describes the ethical procedures followed, as well as sampling, data collection, management and analysis. This chapter concludes with the findings and discussion of findings from this first phase of the study, the e-mail analysis, and explains how these were used to inform the second phase, the focus group study.

### **8.2 Objectives of phase 1, the e-mail analysis**

The objectives of the e-mail analysis were to:

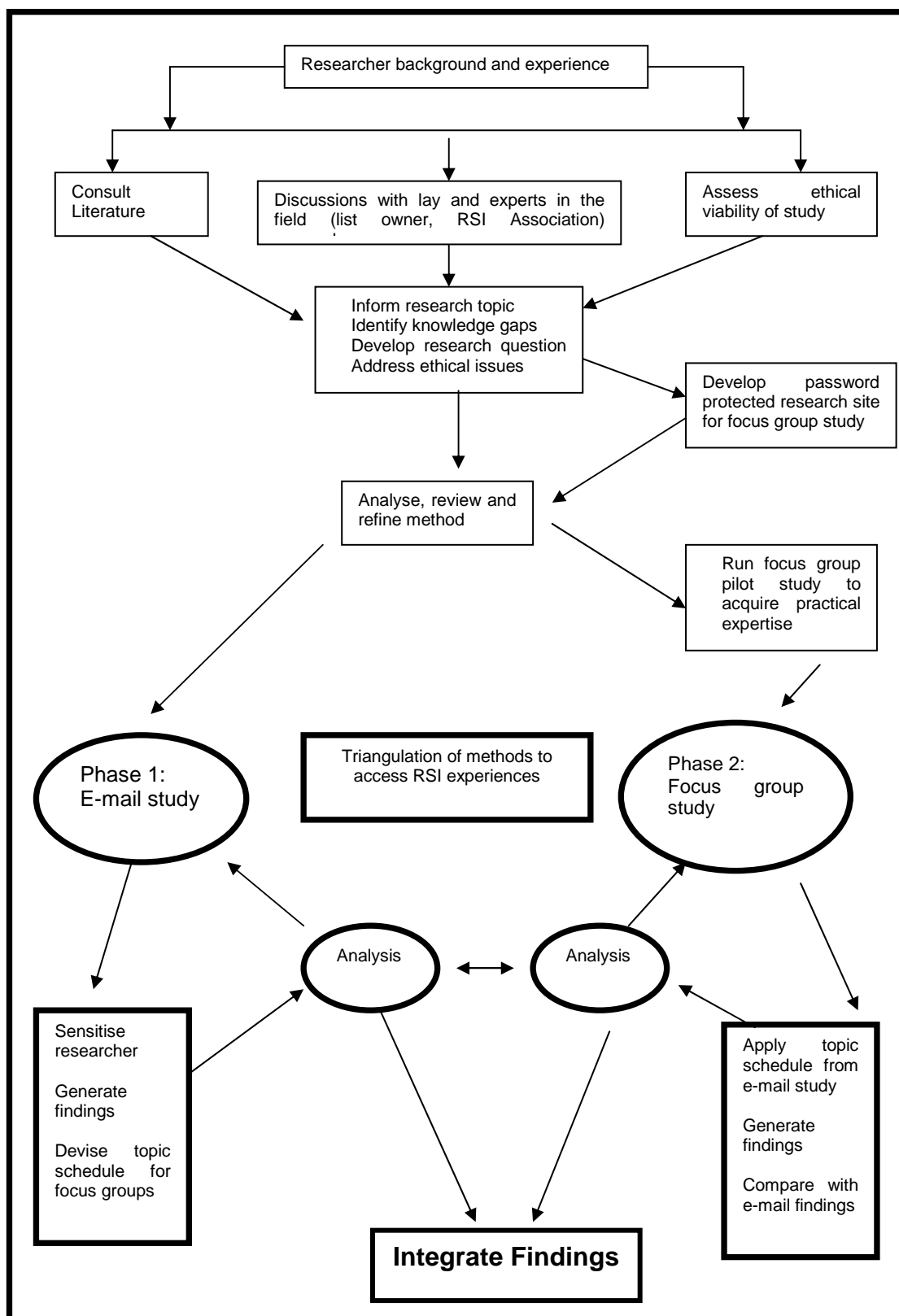
- Categorise RSI sufferers written transcripts of electronic discussions using Morley et al's (1999) domains of pain as a starting point
- Compare and rank the relative frequency of references to each domain of pain experience in the transcripts, to identify topics most frequently discussed
- Identify key influential stakeholders in the RSI experience
- Sensitise researcher to RSI sufferers' experiences prior to running focus groups
- Devise a topic schedule based on e-mail analysis for use in the focus groups

- To assess the utility of this newly developed internet method to achieve the research aims.

### **8.3 Data triangulation**

In this study data triangulation involving documentary analysis of archived support group e-mails and asynchronous online focus groups was used to gain two different perspectives of RSI sufferers' experiences to provide a more comprehensive understanding. The two phases of this research study are highly inter-related despite their separate and linear presentation in the thesis. The findings from one study informed the other in a cyclical process involving continual movement between the e-mail and focus group data and were subsequently synthesised to generate the final integrated findings. This cyclical process is represented diagrammatically in figure 8.1 together with the developmental stages of the research study.

**Figure 8.1: Developmental stages of this research project**



## **8.4 Project rationale**

Gaining an understanding of the illness experience of RSI is important given its increasing significance as an international health and occupational problem. Conrad, (1987) advocated researchers adopted an 'insider perspective' to gain insights into illness experiences. Health care research has traditionally relied heavily on clinical settings to access such insider perspectives. However, such 'over-reliance' on clinical settings has drawn criticism, with researchers being encouraged to explore alternative settings (Conrad, 1990; Thomas and Johnson, 2000; Dworkin et al, 1992). Awareness of this theoretical concern directed a search for participants from a non-clinical setting. The literature suggested access to illness experience accounts could be gained through internet support groups. In particular, internet-based support group archives have been shown to provide rich data to help understand health related problems (Murray and Sixsmith, 1998; Eysenbach and Till, 2001; Sharf, 1997).

Given the benefits of this approach (as previously discussed in Chapter 6), the first phase of this research study involved the documentary analysis of archived support group e-mails as a non-intrusive method to access the experiences of individuals with RSI (discussed in Chapter 7: Methodology and methods). The findings from this phase of the study were used to inform the subsequent phase involving discussions with participants in online focus groups hosted on a password protected internet site created specifically for the study. The e-mail phase of the research is discussed in this chapter whilst the focus group study is covered in the next chapter.

## **8.5 Virtual research venue**

This project was supervised initially by a physiotherapist and then by an occupational therapist based at Queen Margaret University, Edinburgh, Scotland. An important feature of this internet based study was that the focus group research was conducted in cyberspace with neither the researcher nor participants being physically present. The focus groups were conducted from Lausanne, Switzerland but hosted on the main University website in Edinburgh, Scotland.

## 8.6 Ethical Approval

Ethical approval for the study was obtained from Queen Margaret University Ethics Committee. Prior to applying for ethical approval, advice was sought from experts in internet research including Professor Charles Ess, chair of the ethics working group that produced the AoIR guidelines for internet research, Professor James Till and Dr Kate Robson/Stewart, an experienced researcher in internet health care research (Selwyn and Robson, 1998), as well as consulting extant literature in this new and evolving field.

The ethical aspects of this project were challenging since no clear guidelines were available and much was left open to interpretation. These ethical issues were discussed earlier in Chapter 7 Methodology and Methods.

A checklist of ethical issues based on the work of Eysenbach and Till, (2001) was used as a decision-making tool to help establish whether informed consent was required from every individual on the archived e-mail list before use or whether this could be waived, as such data is considered to exist in the public domain. The ethical issues addressed were ascertaining whether users considered the site to be a public or private place, whether access to membership to the site was open or restricted (such as a subscription payable to join), the level of intrusion imposed by the research, the vulnerability of the group and the potential risk of harm. Other factors considered were membership characteristics such as whether the site was for adults or children, the size of the group and whether the community was stable or continually changing. The answers to these questions were found from consulting the list owner, the official list acceptable use policy statement and through direct observation (lurking) on the list. It also involved considerable personal searching for an ethical solution. A detailed account of this decision-making process is provided in Watson et al (2006) in the Appendices.

## **8.7 Locating potential research participants**

To understand the illness experience of RSI, potential participants with the condition had to be located. In view of theoretical concerns regarding the heavy reliance on clinical settings to recruit participants in health care research (Conrad, 1990), the RSI Association, (the national UK body representing the interests of individuals with RSI) was approached for assistance. It was noted that Arskey, (1994, 1998) had previously done this and found this Association helpful.

The RSI Association provided a list of contacts in their national UK network of face to face support groups, and a contact for a UK based RSI internet support group. Both of these sources were explored for their potential to provide insights into RSI experiences and both were subsequently used. Since the literature suggested internet research was a viable alternative to traditional research and cost was an important consideration in this self-funded project, the researcher decided to recruit primarily from the internet support group. This also offered the potential benefit of providing an international dimension to the project and to making a methodological research contribution. However, a group of eight participants who comprised Group 5 in the study were recruited directly through the RSI Association network around the UK and not from the online discussion list.

### **8.7.1 Contact with list owner**

As recommended in the literature, (Murray and Sixsmith, 1998; Eysenbach and Till, 2001), the list owner of the internet support group was contacted prior to the start of the study by e-mail to explain the purpose of the research and to seek permission to 'lurk' (or observe) on the list. The purpose of this observation was to verify whether the support group discussions were compatible with providing an understanding of the RSI experience. During this period of lurking, information relevant for considering the ethical and practical implications of conducting the study was also collected. For example, the policy list statement prohibited anyone contacting list members at their personal e-mail addresses. It also enabled the researcher to establish approximately how many members were on the list, the support group aims, who used the list, how many people actively participated in the list and how

many lurked, how frequently people posted messages, the nature, content and length of postings, types of issues discussed and questions individuals asked of each other. An understanding and consideration of all these issues was necessary in deciding whether or not to proceed with this approach for accessing RSI sufferers' experiences.

From observing the list, it became evident that the content of the e-mail exchanges was very rich covering a wide range of experiences and therefore highly compatible with the research aims. Permission was then sought from the list owner to analyse a sample of the archived e-mails and to recruit participants to the focus groups. Permission to both lurk on the list and to recruit participants to the study was granted by the list owner. Part way through the project, a new list owner took over, so permission to conduct the study was repeated. The new list owner was sent information about the project and given the opportunity of contacting the research team at the University to discuss the research further. After taking up this offer, and privately consulting some long standing members of the support group, the incoming list owner gave his approval to proceed with the study. Subsequently, the researcher personally met with the new list owner in London to consider the best way of recruiting volunteers to the study. It was agreed that the list owner would introduce the researcher to the discussion list first and then she would post to the list. This sequence would reassure list members that the researcher had acted professionally by contacting the list owner for permission to approach the group first and that the researcher's credentials had already been verified by a respected member of the list.

## **8.8 Sampling strategy**

The support group provided information on the experiences of males and females with different RSI conditions (both discrete, clinically accepted entities and non specific diffuse arm pain) in addition to those who were in the process of achieving a diagnosis, individuals at different development stages in the RSI illness cycle, across different age groups, occupations and with a wide range of health care experiences involving the use of both traditional and complementary medicine. The internet also allowed access to RSI experiences across international boundaries as

well as within the UK. Gaining insights into the male RSI experience was an important objective, since some key earlier studies on RSI had focused exclusively on a female perspective (Reid et al, 1991; Dorland and Hattie, 1992).

### **8.8.1 Research context**

This RSI support group mailing list was formed in 1979 by three founding members for the benefit of RSI sufferers. Members use the list as a friendly and supportive place in which to share experiences, obtain advice, help, information and emotional support with others who share and understand their concerns. The list membership was around 350 at the time of the study, many of whom lurked (read e-mails exchanged between others but did not post e-mails themselves). The group culture consisted of a mixture of long serving members who contributed posts frequently, often being the first to respond to newcomer posts, and others. List membership was fluid with people continually joining and leaving the list (more new members than leavers). Whilst some non-sufferers were present on the list (e.g. professionals and researchers with an interest in RSI), the membership consisted predominantly of RSI sufferers with the majority of e-mail traffic being between sufferers. Communication on the list occurred on two distinct levels; within the 'public' discussion group and privately "off list" using private e-mail addresses. The list is not strictly moderated whereby there are stringent rules regarding who is allowed to participate and what occurs in the list, but there is a list owner who deals with any administrative problems. The list is largely autonomous and is guided by rules conducive to positive list participation laid out in its acceptable use policy, which users are expected to adhere to. Many members of the support group consider the list to be an extremely valuable source of information which cannot easily be found elsewhere, as well as providing support. Whilst this list is predominantly UK based, there are also subscribers from other countries.

This internet support group was considered highly suited to providing the rich detail and broad range of experiences sought in this study to understand the experience of RSI.



### **8.8.2 Sampling period**

In this e-mail study, a retrospective sample from 1 March to 31 August 2001 was taken. This extended engagement was intended to provide a breadth of RSI experiences and to minimise the risk of obtaining an unrepresentative 'snapshot' of sufferers' experience. Such circumstances could arise due to seasonal variations in e-mail volume or periods when the discussions might be dominated by particular "hot topics" which were not representative of the day to day use of the list. This particular period was selected purely on pragmatic grounds of representing the last complete set of records covering a 6 month period available on the archives.

### **8.8.3 Inclusion criteria applied to sample**

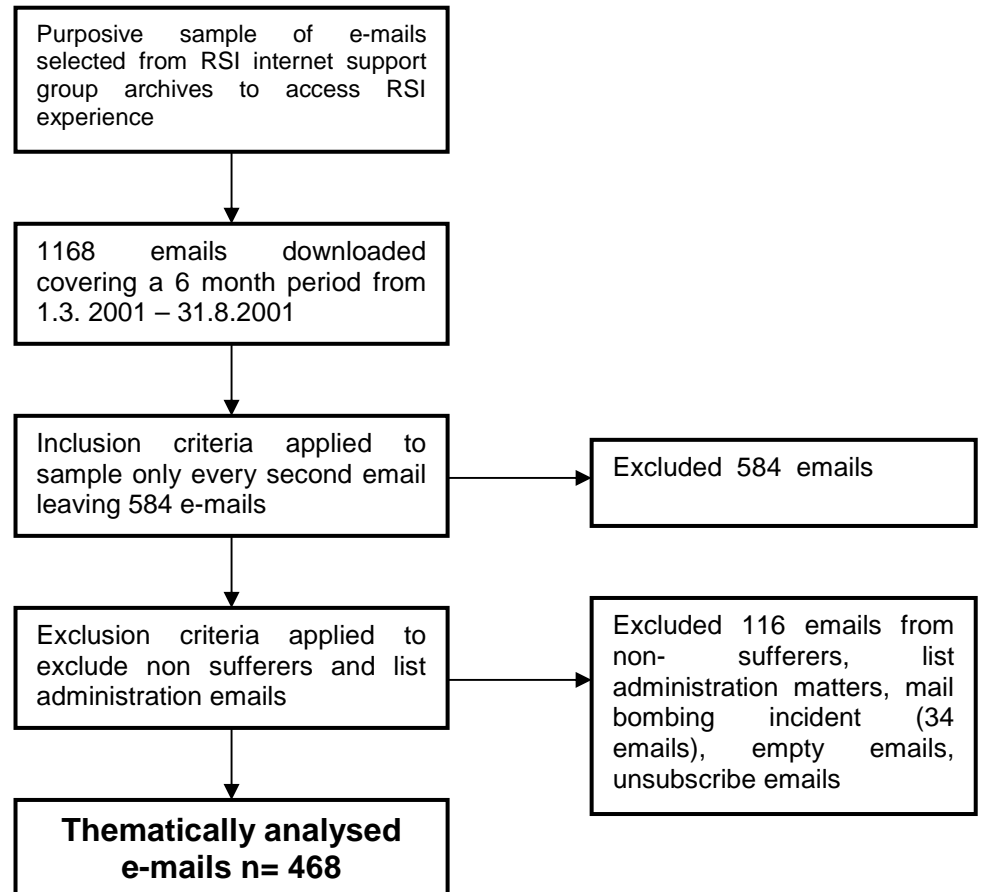
The inclusion criterion was all e-mails logged in the archives for a six month period from 1 March to 31 August 2001.

E-mail messages were initially read and re read to gain an overall impression of the data and initial insights into the RSI experience. The aim of the readings were to become familiar with the content of the e-mails, decide how many of the e-mails to sample, understand the nature and content of the e-mails and to distinguish between RSI sufferers e-mails and other e-mails such as list administration matters. These readings indicated that some of the e-mails were quite long in view of which, a decision was taken to sample only every other e-mail. Confidence was gained that this approach would not compromise the integrity of the data, since many e-mails contained extracts from previous e-mails which were used by members to clarify their response, providing confidence that too much important data would not be lost by doing this. A longer six month sampling period using every second e-mail was considered preferable to a complete record for a shorter three month period, as this extended time frame would include a greater breadth of experiences, ensure data saturation had occurred and allow changes over time to be observed.

#### **8.8.4 Exclusion criteria applied to sample**

Next, exclusion criteria were applied to remove e-mails from people who were known to be non-sufferers, such as a professional ergonomics specialist, a physiotherapist, a computer equipment designer, a representative of the company hosting the site, a voice recognition consultant and a Pilates teacher. Also removed were e-mails pertaining to general list administration matters such virus threats or a request that list members use the “off topic” heading if the e-mail subject matter did not relate directly to RSI. Also excluded were 34 e-mails relating to a “mail bombing” incident in which a female repeatedly posted e-mails to the list asking to be unsubscribed, despite being given instructions on how to do this. In her frustration, she sent multiple e-mails to the list, which prompted some angry responses from list members. This procedure is summarised in figure 8.2:

**Fig 8.2 Sampling procedure for e-mail analysis**



## **8.9 Data Management, Storage and Protection**

E-mails were downloaded from the support group archives onto the researcher's own computer in the same chronological order as in the archives. In addition, e-mails posted by each person were counted to ascertain the average number of e-mails posted and who the most prolific e-mailers were to gauge the balance of views represented. Each e-mail author was allocated an identifying letter and number and all e-mails from that individual were allocated successive numbers.

Efforts were also made where possible to identify the author's gender from the e-mail. Paper copies of the transcripts were stored in six lever arch files which were accessible only to the researcher.

All data was stored on the researcher's private pc, used only by the researcher. To maintain anonymity, participants' names, addresses and other potentially identifying features were removed from any data presented. At the end of the research, all files related to the data will be destroyed. Back up copies of all data were made since the data collected would have been difficult to replace if lost.

### **8.9.1 Transcription**

This research project was entirely computer-based which meant that the e-mails exchanged within the support group were immediately electronically recorded, exactly as typed by the authors, and therefore did not require transcription. In computer mediated communication, participants "type in their own data" (Herring, 1996), removing transcription errors such as punctuation, which can significantly change meaning.

### **8.9.2 Awareness of computer paralanguage**

However, of greater concern when using electronic communication is how this form of communication differs from face to face communication (as previously discussed in Chapter 6). An awareness of computer paralanguage was considered important for understanding meaning in the e-mails.

### **8.9.3 Use of quotes**

Early observations of this online research community indicated that some individuals in this support group were in distress due to their illness and also that a small number were involved in ongoing litigation. This, along with other factors considered by addressing a check list of questions recommended by Eysenbach and Till, (2001), influenced the researcher's decision to refrain from using direct quotes from

the e-mail data since it had been considered practically unfeasible to obtain individual consent from every participant on the list. It was considered that the time involved in doing this, the likelihood of tracing all past participants on the list given the ephemeral nature of internet communication would have been prohibitive and would have provided at best a very fragmented picture. The approach taken to paraphrase discussions was considered an ethically acceptable compromise.

## **8.10 Data Analysis Procedure**

The analysis was undertaken in two stages; manually and computer assisted. Initially, hard copies of the data were read on a line by line basis (Strauss and Corbin, 1998). The text margins were annotated with words or phrases that reflected the nature and content of the discussions and linked to aspects of their experience. Colored marker pens were used to assist initial code development and labeling of data. The manual coding was followed by a computer assisted analysis in which CAQDAS - Nvivo was used to sort, manage, organise and manipulate the data. These two stages of analysis are considered next.

### **8.10.1 Modifying Morley *et al*'s framework**

Morley *et al*'s (1999) framework was used in this study because it afforded a useful and flexible starting point for analysis allowing the categories related to pain experience to be expanded or collapsed to accommodate the e-mail data. For example, it was noticed that financial and legal matters were discussed in the e-mails but could not be accommodated within Morley *et al*'s (1999) existing framework since this was based on pain assessment in the context of clinical settings. An additional category for the financial impact of RSI was therefore created. It was also noticed that many groups of people exerted an influence on sufferers' experience of RSI, such as employers, health professionals, family and friends. It was felt useful to know who the various stakeholders in RSI were so a further category was created for this information. The 'pain behavior' category was interpreted very narrowly as referring to visual observations of patients' pain behavior such as limping, grimacing or guarded behavior which were visual

assessments made when a patient presented at the clinic. Since the nature of the internet medium meant such visual cues were absent, this category was only used minimally. However, where sufferers talked about their pain behaviour, such as stating that he or she avoided going out for fear of someone accidentally hurting their arm, this was coded as an instance of pain related behaviour. Pain related behaviour in terms of what sufferers felt they could or could not do was recorded separately.

### **8.10.2 Inductive analysis**

Next, the large volume of data collected under each of Morley's very broad categories of pain experience was inductively analysed to gain a more comprehensive understanding of the depth and breadth of data. In this way, codes were refined by re-analysing the text actually coded within each node Gibbs, (2002). For example, from inductive analysis, the theoretically derived category of 'pain' was found to encompass different dimensions of pain such as its onset, intensity, duration, bodily location, pain sensations and symptoms, its ability to spread, its inconsistency and unpredictability as well as its unpleasantness.

## **8.11 Findings and discussion of e-mail study**

### **8.11.1 Introduction**

As previously discussed in Chapter 5 on illness experience, Schneider and Conrad, (1983) state that an insider's perspective of illness focused on people's everyday lives, lived with and in spite of illness. Important factors included how people first noticed something was wrong, what this meant to them and what lay theories and explanations were used to make sense of illness. Such accounts considered what prompted medical help seeking, noticing what concerns and expectations people had, the impact diagnosis had on them and how they coped with a medical label. Also considered important by Schneider and Conrad, (1983) were how individuals managed their daily lives, the impact of illness on their relationships with family,

friends and work associates and how their disorder changed them in their own eyes and in the eyes of others.

Guided by Schneider and Conrad's (1983) broad definition of an insider's perspective, a thematic analysis was undertaken on the e-mail data to explore, analyse, describe and interpret sufferers' RSI experiences.

### **8.11.2 E-mail support group study sample**

From the archived e-mails, RSI affects both males and females employed in different occupations and sectors of the workforce as well as students and homemakers. Many of the participants in this study sample were employed predominantly in office based jobs. Employees included those working in at least six different universities, an editor, novelist, an emergency call handler, and two translators, those employed in various information technology roles in addition to secretarial/administrative staff. Non-office-based workers represented in the group included professional musicians, a sonographer, and a post office and production line worker. The list although predominantly UK based, did have subscribers from other countries. Different age groups and RSI diagnoses were included in the group based on self report. This information was contained in the e-mail postings made by sufferers.

### **8.11.3 Restatement of aims of e-mail analysis**

The overall aim of this first phase of the study was to gain insights into the experience of RSI from the perspective of the individual from analysing archived support group e-mails. A thematic analysis was undertaken to explore, analyse, describe and interpret the experiences of RSI.

The total number of people contributing e-mails during the 6 month research period was 204. The estimated list membership at that time was 300-350 people, suggesting around a third were lurkers. The most prolific e-mailers were a mixture of

long serving members and the list administrator. The maximum number of e-mails posted during that 6 month period was 65 e-mails posted by two participants, neither of whom were the list owner.

<b>Number of e-mails posted</b>	<b>Number of people who posted that number of e-mails</b>
1	75
2	34
3	19
4	16
5	4
6	6
7	8
8	7
9	5
10	1
11-20	19
21-30	3
31-40	3
41-50	1
51-60	1
61-70	2
1168 = total postings in 6 months	204 = total no. of people contributing to posts

A significant proportion of the online population may not directly contribute to the discussions but only read the messages of others, termed lurking (Davison et al, 2000). From a research perspective this raises issues about what is more meaningful to record; the number of participants in the group (including those who lurk) or the number of people who actively participate in group discussions (Davison et al, 2000).

The findings in this study indicate that most of the e-mail postings are made by a minority of participants. These findings are consistent with other studies such as Barker's study of a FM support group in which a total of 1814 e-mail postings were made in a 12 month period by 249 participants. Barker, (2008) noted that 45.4% of



participants only posted one message whilst 22.5% of members only posted 2 or 3 entries. The most active participant in Barker's study contributed 145 posts over the year. The usage pattern showed that 19 individuals on the list (7%) contributed over 50% of the postings. Barker, (2008) commented that the most frequent participants were likely to be lurkers.

The following table provides a template indicating the nature of the data coded under each of Morley's pain domains and how many individuals contributed discussion related to each domain.

**Table 8.1: table showing number of individuals contributing to e-mail discussions related to each pain domain**

<b>Pain experience categories (from Morley et al, 1999)</b>	<b>Nature of information coded under each pain domain</b>	<b>Number of individuals contributing to discussions</b>
Pain experience	References to pain intensity, duration, inconsistency, symptoms, sensations, unpredictability, ability to spread , unpleasantness, difficulty communicating experiences	46
Mood/affect	Feelings about depression, feeling low or down, anxiety, need for emotional support	14
Cognitive appraisal and coping	Judgments made about coping with pain and strategies used to manage pain (positive and negative) e.g. information seeking, seeking support, finding ways to continue working, e.g. learning to use and adapting to use voice recognition software, seeking recommendations for treatments, purchasing appliances to make life easier, changed attitude. Also denial and passive coping	92
Pain behaviour	Narrowly interpreted to mean behavior which signalled presence of pain e.g. facial expressions, limping, grimacing, guarding. Physical tasks people were unable to carry out were recorded under social role functioning e.g. unable to work, difficulties in performing routine activities.	6
Biology/physical fitness	Assessment of biological function, loss of grip strength, blotches/ marks on skin, extreme sensitivity to heat	12
Social role functioning	How RSI interfered with or changed sufferers' social roles and functioning such as inability to work, sick leave, consequences of changes on family and social roles. All functional limitations, e.g. driving, employment, cutting up food, self grooming activates, brushing teeth etc	63
Use of health care system	Clinic visits, GP consultations, diagnosis issues, searching for 'good' doctors, comments about health professionals, drugs taken, and (in) effectiveness of treatment, drug side effects, fear of drug dependency, range of orthodox and complementary therapies tried	90
Legal/financial	Talk related to solicitors, industrial injuries benefit, disability living allowance (DLA), compensation, insurance, loss of income, employers unwillingness to pay for workplace adjustments	30
Miscellaneous	List administration matters, humour, personal chit chat such as congratulations on getting a job, birth of baby , thanks, etc.	18

In the following section, the findings from this study have been presented under three overarching themes developed from the data and subsequently used to inform the focus group study:

1. Coping with RSI
2. Healthcare use/medical help seeking
3. Interference of RSI in social role performance.

#### **8.11.4 Overarching theme 1: Coping with RSI**

Sub themes:

- RSI onset,
- interpreting symptoms and factors influencing the decision to seek medical help
- importance of support from stakeholders,
- strategies used to manage RSI pain and its limitations
- information seeking to gain understanding and develop expertise, delegating, reorganising or changing work patterns, finding/adjusting to new and different ways of doing things e.g. new technology VRS, pacing, cutting back, becoming more organised,
- keeping body in top form to aid recovery,
- destressing, thinking differently, lowering/changing expectations.

##### *8.11.4.1 Recognising RSI onset*

The sufferers' experience of RSI usually began with an insidious onset in which the subtle changes sensed were initially difficult to recognise and it was difficult retrospectively to pinpoint a precise time which clearly marked the point of onset. Discriminating between the symptoms felt during onset from the "normal aches and pains" previously experienced was problematic. These gradual changes in

symptoms lead some sufferers to feel that RSI had crept up on them and established itself almost unnoticed. Sufferers were uncertain whether the symptoms were sufficiently serious to warrant medical attention and wondered how long they should wait before taking action. This difficulty in discerning and interpreting symptoms as 'serious', combined with the underlying hope that they would disappear of their own accord, resulted in delays in seeking medical help. With hindsight, sufferers saw this delay as detrimental since symptoms had the potential to deteriorate rapidly in a matter of weeks. Conversely, in other sufferers, RSI onset could be quite sudden and dramatic which sufferers could remember in detail as a memorable event indicating that 'something was wrong'. In both types of onset, once sufferers had developed painful symptoms, they sought medical help for an explanation to help make sense of what was happening to them. Bodily symptoms were interpreted as 'something wrong' which required some counteractive action; obtaining a diagnosis was an important part of this understanding and was a primary reason for consulting health professionals. The motivation for sufferers to seek medical help was the persistence of pain and other symptoms overnight or over the weekend and its effects spilling over into other aspects of their lives.

#### *8.11.4.2 Interpreting symptoms*

Sufferers described the undesirable and unpleasant aspects of their symptoms differently depending on whether they felt others could understand and relate to their pain and suffering or not. When talking to fellow sufferers within the support group with whom they shared a common framework of understanding, sufferers referred to their symptoms only as 'the pain'. At other times, when speaking to non-sufferers, sufferers used metaphors, or adjectives to compare RSI pain to types of pain they thought others might relate to more easily, such as a very bad toothache.

RSI symptoms often manifested themselves as tingling and numbness (also described as pins and needles) felt in the fingers, hands, wrists and arms along with pain radiating across the top of the hand or a burning sensation. Other symptoms included 'soreness' in the arms or hands denoting tenderness or extreme sensitivity. This sore area could be very hypersensitive and deterred one individual from venturing outside the home to avoid the risk of being accidentally being hurt by others. Manipulating everyday objects in the hands became painful for many from

weakness or from soreness felt around the thumb joint. Some reported feeling a sensation of swelling in the wrist or hands which was occasionally accompanied by physical swelling. The symptoms described by sufferers are consistent with those of neuropathic pain which usually has no visible signs and is difficult to detect and treat. These pain mechanisms were discussed in the earlier chapter on pain and pain mechanisms.

Sufferers also reported sharp and shooting pains and twinges. Twinges were taken as a warning sign that more intense pain would follow if steps were not taken to prevent pain from becoming worse and afforded sufferers a way of managing pain. Other symptoms experienced included general aching, a feeling of fatigue, exhaustion and weakness and a sense that the limbs felt heavy.

The pain symptoms were sensed in different parts of the body but predominantly in the fingers, hands, wrists, arms, shoulder and neck. The intensity and location of symptoms could change where for example pain experienced in the hand/wrist on one side of the body could spread to the other side, particularly if sufferers compensated, for instance by switching over to using the computer mouse with the other hand or if they alternated between both hands. Sufferers were often perplexed by the lack of correlation between symptoms felt and activity undertaken, which meant that managing pain became more complicated than simply regulating activities which were known to exacerbate pain.

#### *8.11.4.3 Explanations for developing RSI*

The majority of sufferers firmly believed that their RSI was a physical injury which they attributed to their paid employment. Common explanations given for RSI were that it was a result of muscle overuse, insufficient rest, poor posture or working in a stressful and poor work environment. Sufferers attributed the pain and discomfort experienced to an injury usually acquired through work, and interpreted pain as being due to ongoing tissue damage. They perceived rest as being essential to allow healing to occur. A similar connection between pain and injury was noted in back pain patients in a study by Osborne and Smith, (1998) and Rhodes et al, (1999).

In this study, whilst work was clearly considered to be the primary cause of RSI, alternative explanations given by a minority of sufferers included the existence of some pre-disposing structural weakness arising from a previous injury, such as whiplash injury. In addition, many sufferers alluded to the role of stress in the development of RSI, and acknowledged its ability to exacerbate RSI, but rejected the notion that stress alone was the main cause of RSI as this implied RSI had a psychological basis which contradicted their view of RSI as a mechanical injury. One participant in this sample who was told by her employer that she was stressed and needed psychological counselling for her pain disagreed with her employer arguing that she was stressed because of the pain, not in pain because she was stressed. This argument of which was the antecedent and which was the successor out of stress and pain was a recurring issue in the data.

In cases of diffuse non-specific RSI where no clinical diagnosis could be made, health professionals were perceived by sufferers to attribute RSI to psychological causes by default which RSI sufferers were keen to dispel. Jackson, (1992, 2000) highlighted that individuals rejected a psychological basis for their condition because this was deemed undesirable because of its negative connotations of mental illness. A psychological basis for RSI was also given by medical professionals in Reid et al's (1991) Australian study of women with RSI and also in other patient groups such as back pain sufferers (Osborne and Smith, 1998) and CFS (Ware, 1992). This attribution of RSI by doctors and others to psychological causes is an important issue in RSI and is discussed in more detail in the integrated discussion alongside problematic encounters with medical professionals.

#### *8.11.4.4 Heightened awareness of body and stabilising injury*

Sufferers developed a heightened awareness of their body after getting RSI and considered that exercise, maintaining physical mobility and emotional well being were all important factors in facilitating recovery. Some sufferers invested a considerable amount of money and effort in ensuring that their body was kept in optimal form to give it the best possible chance of recovery from RSI, consistent with their views that it was a mechanical injury which could be repaired. This was

achieved by taking vitamin and mineral supplements, eating a healthier diet and learning to relax and de stress using various techniques. Some individuals who had suffered with RSI for some time, focused on preventing RSI from deteriorating any further and trying to stabilise it rather than aiming for recovery. This increased awareness or consciousness of the body following injury or illness has been discussed by several authors in the literature. It has been stated that the normally 'silent' body in the absence of disease, is suddenly brought to the forefront in illness (Idler, 1979; van Manen, 1998). Van Manen also suggested that illness or injury changed the relationship between the person and their body. Leder, (1990) suggested that the body was characterised by its absence in good health where it receded into the background of daily existence. However, in illness or injury the body reappeared into consciousness or to use his term, "dys-appeared" in that it became noticeable but in a negative way (Bendelow and Williams, 1996).

#### *8.11.4.5 Importance of social support - stakeholders*

One of the extra categories developed in the early analysis was to document the stakeholders who influenced the experience of RSI. These groups were important as sufferers often looked to them for support in coping with and recovering from RSI. The principal social groups from whom help was sought in RSI were fellow sufferers in the online support group, medical and legal professionals, workplace personnel such as employers, managers and work colleagues, occupational physicians, human resources personnel, and government agencies, such as the Department of Social Security (DSS), the government's Disability Living Allowance office (DLA), and Access to Work for financial support and equipment. Emotional and practical support was also obtained from close family, friends, neighbours, the internet and other media. The nature and level of support received by sufferers from these various groups and individuals contributed significantly to their experience of RSI. Sufferers often needed emotional, informational, financial and practical support to help them cope with illness. The support provided by these various groups is discussed next.

#### *8.11.4.6 Peer support - the internet based support group*

One principal source of support for this group of RSI sufferers was from other members of the internet support group where relevant information and advice was sought from those more experienced and knowledgeable than themselves and who by virtue of having RSI themselves really understood the complexities of RSI. Sufferers highly valued this experiential support, sometimes over-riding the opinions of medical professionals.

The suffering endured by individuals during their daily living was mitigated in the online group setting by having others who believed and understood them. However, sufferers acknowledged that others who had not directly experienced chronic pain and its idiosyncrasies could not really appreciate the difficulties sufferers had to contend with. The unique support group setting provided them with a place to escape to, providing a temporary respite from having their pain and suffering challenged in their off-line world.

When sufferers were unable to sleep, they were able to go online and contact others at what would otherwise be considered unsociable hours, for example during the middle of the night. Support from fellow sufferers in the online group allowed them to learn about everything from the side effects of drugs to the interpretation of health and safety legislation from others. Peer support was highly valued in helping sufferers to make decisions about the many life choices which confronted them. Sufferers viewed the support group as a place where they could be honest, where they didn't need to explain everything as others understood them, where they could bounce ideas off each other and had the opportunity to clarify things which they didn't understand. Sufferers were empowered to exercise their right to 'good' health care and felt less isolated because they could share their experiences. The main value however, was the emotional support provided through others validating their experiences and sharing practical advice and insights into coping. By comparing and sharing experiences, sufferers were better able to understand and put into a wider context their own situation. The support group afforded sufferers an outlet through which to express inner thoughts which had entered their minds, but had not previously been aired, such as concern that they may have fibromyalgia underlying the RSI.



Members in the support group tried to keep a positive outlook and encouraged each other to overcome obstacles and to pursue their dreams despite having RSI. Practical solutions were offered for example on how to overcome potential difficulties such as note-taking during lectures by using a tape recorder instead. Practical information learned elsewhere, such as advice given at a pain clinic on pacing techniques, was shared with the whole group, which added to the attraction of the internet support group as a valuable source of diverse information and support.

#### *8.11.4.7 Support in the workplace*

The impact of RSI in the context of paid employment was felt most markedly for many sufferers where their workplace encounters with others had a significant bearing on the outcome of their RSI experience. Many RSI sufferers needed and expected some level of support from their workplace in order to accommodate RSI. This could entail modifying work practices and routines, equipment or work environment. These changes at work ranged from minor ergonomic adjustments at one end of the spectrum to a complete change of career at the other, where sufferers felt this was the only option. Others felt they must avoid or reduce exposure to whatever was causing or exacerbating pain. Whilst health professionals often advised sufferers to find alternative ways of working or earning a living, this suggestion was practically untenable for many since they felt using computers was something they had always done, or was something that they were competent at and had trained for. One individual discussed how despite making ergonomic adjustments to their workstation, outsourcing typing, operating the mouse with the other hand (which resulted in pain spreading to the other hand) and consulting various health professionals, had not managed to eliminate RSI and had therefore decided to embark on a completely different career. In conjunction with employers, sufferers accommodated RSI in different ways such as reducing their work hours, changing their job or nature of duties undertaken, learning to use new technology such as voice recognition software or using alternative pointing devices as well as making postural adjustments.

Sufferers experiences in the workplace suggested most perceived their employers as unsupportive. Whilst many sufferers made negative comments about their employer, a very small number said they had a supportive employer based on the rapidity with which their employer had implemented ergonomic changes to help resolve and accommodate their problems. Generally however sufferers felt employers paid insufficient attention to what was really happening in the work place or felt that employers chose to ignore it. Even when employers were fully aware of workplace problems, RSI sufferers felt that employers only fulfilled their minimal legal obligations under health and safety legislation as a token gesture, rather than a genuine commitment and opportunity to improve working conditions. Sufferers were perturbed by some employers' perceived lack of concern regarding the high incidence of RSI amongst their staff, the high workloads imposed on employees and the stress levels endured by them. Some sufferers felt that employers considered employees to be dispensable, and pushed them to their limits until they burnt out, and then replaced them by someone else who would repeat the cycle. Employers were seen by sufferers to be more concerned about making a financial profit than the well being of their employees and were perceived to be reluctant to invest any finances to help individuals.

Sufferers work colleagues were also generally perceived to be unsupportive. This finding is consistent with Dorland and Hattie's (1992) study into women with RSI who reported that their work colleagues were "psychologically disruptive". Many sufferers also felt they had received little support from either union representatives or solicitors. Recognising the serious consequences RSI could have for individuals, some sufferers felt obligated to alert their work colleagues to the potential risks of RSI but at the same time feared reprisals if they became too vociferous. They also became frustrated if their attempts to warn their work colleagues were not taken seriously.

#### *8.11.4.8 Support from family and friends*

Whilst sufferers outwardly stated that their families were supportive, this was usually accompanied by an underlying qualification that neither close family, nor others who do not suffer from the condition, could truly understand what their experience was like. Sufferers found it difficult to share or explain the pain they sensed inside their

body. This inaccessibility of pain to others is well documented in the literature and was discussed in Chapter 2. Whilst family relationships were not often openly discussed, there were indications that RSI created tension and conflict such as resentment about the loss of independence and having to depend on others. Although the internet medium used in this study could have contributed to sufferers' reluctance to discuss family relationships in the public domain of the internet, there is evidence that this may also be mirrored in face-to-face settings. One explanation for the reluctance to talk about more personal relationships may be that sufferers felt they would be betraying or being disloyal to close family and friends if they openly stated that their families did not understand or support them. In addition the list appeared to be more focused on work related and health care issues than personal issues. This may not be surprising in an open forum such as the internet.

#### *8.11.4.9 Strategies used to manage RSI and pain*

RSI was managed in different ways by different individuals using strategies ranging from small scale alterations in their work station to major life changes such as the decision to retrain for another career. Some sufferers were still in the process of coming to terms with RSI and did not have a clear set of strategies. A common strategy used in this sample group was the acquisition of information and knowledge to help them understand more fully what RSI was and how it might impact on their life, what the prognosis was and the treatment options open to them. This information was gathered from different sources. A key source of information was the support group but also health professionals, work place, internet, social networks of family and friends. Peolsson et al (2000) discussed how having chronic pain was an "apprenticeship", during which time individuals learned about chronic pain and this seems to be pertinent to this group.

Sufferers devised a variety of strategies to manage their pain including taking medically prescribed drugs to manage pain symptoms such as painkillers, anti inflammatory drugs and anti-depressants. Some felt that depression was inevitable given their difficult situation but argued vehemently that depression was not pre-existing but was a secondary effect of getting RSI. Sufferers tried a multitude of treatments, the effectiveness of which could only be found by a process of trial and

error. Listening to the body became a strategy whereby sufferers became attuned to indications of more serious pending pain such as “twinges”. Over time, sufferers could gauge what aggravated pain and learned to regulate it by minimising, avoiding or adjusting to the problem.

Sufferers explored strategies to address possible underlying causes or contributory factors such as managing stress and tension and taking extra vitamin supplements to keep the body in “peak form” to give it the best possible chance of recovery. Sufferers however were confused about what level of pain was acceptable and should be “worked through” and when they might be “overdoing things” and exacerbating the underlying condition. This resulted partly from receiving conflicting advice from health professionals regarding the need for rest and the need to keep working. Getting the right balance between remaining active and resting was considered difficult. Strategies used by sufferers to accommodate RSI into their daily lives included learning new and different ways of doing things which avoided or minimised discomfort and pain. Examples included changing the type of bag carried to one which could be carried on the back or across the chest to free the hands from directly supporting any weight. Shopping habits were changed such as purchasing groceries in smaller quantities and using only those supermarkets which involved the minimum amount of lifting, carrying and walking. One sufferer was frustrated that the orange disabled stickers were reserved only for those with difficulty walking and not given to those who had difficulty lifting and carrying. New activities were taken up or former ones restarted, such as running. One participant who went running said this was a way of regaining some control over life by using the legs which still co-operated in a way the hands/arms did not.

Strategies for coping with RSI included becoming more aware of tension in the body and learning to relax by dropping shoulders when hunched either at the computer or at other times, such as walking. Opening doors by sliding a foot inside and then using the shoulder to take the weight to avoid the use of the hands was another strategy used or feet were used to push or pull a door. One member said they had become more organised and carried with them pre-printed address labels to avoid having to write out their name and address on forms.

Changes were made in ways of working, such as going to see colleagues within the same organisation in person rather than sending them an e-mail or phoning, which was considered a return to using 'more traditional' means of communication. Others mixed typing short e-mails manually with using voice recognition software (VRS) for longer e-mails and documents. It was considered that by combining manual typing with VRS the body was exposed to a greater variety of movements.

Another important way of managing their condition was being able to talk to others about it and to be able to discuss their concerns which the online support group forum provided. Other strategies used by sufferers involved delegating tasks to others but which several individuals said they felt uncomfortable about having to depend on others. In addition to strategies involving physical adjustments to their lives, sufferers also changed mental attitudes towards work and life in general.

#### **8.11.5 Overarching theme 2: Medical help seeking and significance of a diagnosis**

##### **Sub themes:**

- Initial encounter with GP
- Variability in medical care and knowledge of RSI
- The centrality and meaning of a diagnosis
- Issues relating to a problematic diagnosis
- Difficult doctors/patient relationships
- Ineffectiveness of treatments
- Use of both traditional medical and complementary therapies
- Wider issues e.g. lack of social awareness

##### *8.11.5.1 Initial encounter with GP*

Medical encounters with health professionals were a key factor influencing sufferers' experience of RSI. In search of an explanation for their painful symptoms, sufferers' first made contact with their own GP with the expectation that health professionals would be able to explain their symptoms, clarify what was wrong with them and

provide some intervention to relieve their pain. For most sufferers finding out what was wrong was synonymous with getting a clinical diagnosis. Securing a diagnosis was of central importance for this group and for many became a major lengthy quest in itself. Sufferers whose RSI was difficult to diagnose had numerous encounters with a range of different health professionals.

During sufferers' encounter with their GP they were routinely prescribed painkillers such as paracetamol, anti-inflammatory drugs such as ibuprofen and sometimes referred to a physiotherapist. If the pain did not respond to the drugs, some individuals requested a different prescription or asked that the dosage be altered. This standard treatment provided by doctors however, was often considered ineffective by sufferers because the medication did not abate their pain or it had undesirable side effects, such as making individuals drowsy, "spaced out" or gave them stomach problems. Additionally sufferers expressed concern that drugs might be masking the pain and in the process, exacerbating the underlying injury. Whilst some sufferers found the physiotherapy treatment to be therapeutic, rarely did it provide a long-term solution to their pain. Sufferers became distressed as a result of their painful symptoms, and returned to their GP for help. However, this distress was sometimes taken to be partly the cause of their pain, for which sufferers were prescribed tricyclic anti-depressants such as Amytriptyline which they were told, was also effective for pain relief at low doses.

The stark realisation that their painful condition might be present long-term and would have to be managed since RSI could not be cured was unexpected news for some. One young participant stated she had believed that by adhering to medical advice and routines such as taking the drugs prescribed by doctors and following the exercises advised by the physiotherapist, her RSI would disappear. The prospect of living with long-term pain had a particularly devastating impact on younger members in the group who were in their early and mid-twenties, who had to confront RSI at a very early stage in their life and working career.

#### *8.11.5.2 Variable standards of treatment and ineffective treatment*

Sufferers' experience of their health care treatment depended heavily on the knowledge, competence and communication skills of the health professionals concerned. It also depended on local health service resources, such as access to experts and waiting times for appointments. The considerable variability in these factors led sufferers to view their treatment and care as ad hoc rather than standardised and treatment could be occasionally good but more usually, poor. Sufferers expected health professionals to both acknowledge their suffering and provide pain relief but for many either one or both of these needs remained unmet. The difficult encounters with health care professionals are considered in more detail in the integrated discussion since these are key factors in shaping the RSI experience from the sufferer's perspective.

Very few sufferers experienced an unproblematic passage through the health care system, with the majority finding it a lengthy, emotionally charged and a physically draining struggle for medical recognition. Some sufferers became more assertive with their GP and requested further diagnostic tests in efforts to "prove" their suffering. They also became proactive in their own health care, by seeking recommendations for knowledgeable RSI experts which they could give to their GP for referral. Sufferers were united in their determination to obtain pain relief and to find the root cause of their pain, at any cost, even if it meant enduring numerous examinations and tests. Sufferers routinely underwent several different diagnostic examinations including MRI scans, nerve conduction tests, Doppler tests and physical examinations by health professionals in the hope of procuring a diagnosis.

Sufferers were so anxious to be rid of the pain that they were willing to "try anything" and tried many treatments. However, if the pain persisted despite these medical interventions, they lost confidence in the medical profession and resorted to complementary therapies and self-management. In most cases, complementary therapies were used alongside traditional medicine rather than replacing it.

Sufferers' whose symptoms persisted were often referred by their GP to a rheumatologist as they were considered to be the most appropriate pain specialists for dealing with RSI. However, sufferers' encounters with rheumatologists were

often unsatisfactory; sufferers' were told that nothing was wrong with them or that the rheumatologist could do nothing for them because the problem was work-related. Sufferers considered it important to have trust in health care professionals' competence in terms of the advice they provided to patients and on how thoroughly they carried out physical examinations ensuring this was done properly rather than a cursory look. If, after undergoing several diagnostic tests, sufferers could still not procure a diagnosis, then the authenticity of their subjective experiences was questioned and they felt disbelieved. Sufferers were either suspected of having ulterior motives or their symptoms were attributed to psychological causes. Sufferers who were denied medical validation were left open to suspicion and doubt regarding the truthfulness of their reported symptoms. The significance then of a diagnosis in these cases became much more complex than simply a routine medical practicality to find out what was wrong.

#### *8.11.5.3 Diagnosable and non-diagnosable RSI*

Some sufferers were aware that the generic RSI label subsumed conditions which could be further clinically categorised into those types of RSI which could be diagnosed (therefore often interpreted as "provable and genuine") and those which could not be diagnosed using diagnostic tests. Those forms of RSI which could not be diagnosed and therefore left the individual with unexplained symptoms, usually presented sufferers (and clinicians) with the most difficulty because they lacked any objective markers of disease meaning that sufferers' self-report had to be accepted at face value. Sufferers even made this distinction amongst themselves that some had 'proper' officially recognised types of RSI. The lack of a diagnosis had far reaching consequences for the individual during medical help-seeking efforts and later when not having a diagnosis spilled over into other aspects of their lives such as at work and in social relationships, ultimately diminishing their sense of self and identity.

#### *8.11.5.4 Multiple meanings of a diagnosis*

Sufferers invested great effort in pursuing a diagnosis and attached great significance to it, despite their often unsatisfactory encounters with health



professionals and the negative results which followed diagnostic tests which failed to reveal anything out of the ordinary. A diagnosis took on different meanings for different people and could have multiple meanings for any one individual. A major significance of a diagnosis was that it provided sufferers with medical legitimacy which was seen as medical endorsement of their pain and suffering as being genuine rather than fabricated. Other meanings given to a diagnosis were that only by establishing the cause of the symptoms would it be possible to assess the gravity of the illness and to eliminate more serious underlying conditions. A diagnosis represented a crucial point in sufferers' recovery, providing a basis for finding the best treatment. Some sufferers questioned the medical logic of treating a condition without knowing what it was (establishing a diagnosis). Another main benefit of a diagnosis was that it could allow access to benefits such as sick leave and modifications to the work environment and equipment. For a very small minority of RSI sufferers who were pursuing a legal compensation cases, a diagnosis provided vital medical evidence to support their claim and had the potential to determine the legal outcome. At a wider social level, a diagnosis was important as it provided a label and a way of communicating with others about their condition. Having a diagnosis was clearly considered to be an important requirement to be socially accepted. Clinically diagnosable conditions such as carpal tunnel syndrome were accepted as genuine conditions, whereas undiagnosable, non-specific types of RSI received a mixed reaction from others resulting in different levels of social acceptance for the various conditions categorised as RSI. Whilst a diagnosable condition maybe more accepted by the medical profession, the findings in this study suggest that both diagnosable and non-diagnosable conditions can be problematic for sufferers in terms of pain management.

#### *8.11.5.5 Meaning of negative diagnostic tests*

With each new medical encounter came renewed hopes that perhaps this time the medical tests would reveal something significant. Disappointment followed when sufferers' hopes were dashed, as was often the case. With every diagnostic test which showed nothing of concern, sufferers felt more hopeless and even questioned their own sanity and whether their pain was "all in the mind" after all. The more protracted and elusive the diagnosis became, the more disillusioned sufferers felt.

Repeated unsuccessful attempts to obtain a diagnosis in which the results did not verify the suspected diagnosis meant sufferers would have to endure another diagnostic cycle with all the accompanying trauma, anxiety and uncertainty this entailed. Sufferers found it demoralising and heart breaking having to undergo yet more tests such as MRI scans and nerve conduction tests. However, so desperate was their need to know what was wrong and to procure a diagnosis that they were willing to persevere with being passed around the health system from person to person to get this. When several treatments failed, they were labelled as being 'a hopeless case' by health professionals, a term resented by sufferers.

In cases where no diagnosis could be made, sufferers constantly felt obliged to explain and convince others of their pain. Enormous relief was experienced if medical evidence was found to "prove" their condition as being genuine and physical as this carried greater kudos than imaginary or psychological illnesses.

#### *8.11.5.6 Difficulties encountered in getting a diagnosis*

Procuring a diagnosis was problematic because sufferers' symptoms were difficult for clinicians to define since they lacked objective signs of disease, or symptoms overlapped with other conditions, which resulted in sufferers being given one or more incorrect diagnoses. Moreover, the RSI label is not a neutral diagnosis but carries with it legal connotations of compensation claims against the employer which also has implications for its diagnosis. These and other factors made reaching a clinical decision difficult.

Given these difficulties, the process of obtaining a diagnosis was lengthy and could potentially take several years, during which time sufferers were "passed from one specialist to another" in efforts to reach some clinical consensus regarding their diagnosis. Metaphors such as "passed around", "bounced back" implied sufferers felt they were being sent on a haphazard journey through the health care system rather than following a systematic, orderly or logical route. In a few cases sufferers believed that some health professionals deliberately avoided attaching a medical name to their condition for fear of being drawn into a legal battle. Sufferers reported

that whilst RSI was intimated in discussions, it was not officially recorded on their patient record.

#### *8.11.5.7 Consequences of the lack of diagnosis*

The consequences of either being denied or being unable to obtain a medical diagnosis were that sufferers were denied access to financial and other benefits since some employers refused to make any adjustments in the workplace without conclusive proof that the sufferer had RSI and that it had been caused by their work.

The examples above highlight how objective clinical measures appeared to supersede subjective experience as more reliable markers of illness and “proof” or evidence of suffering. Sufferers’ bodily experiences and pain sensations carried little weight unless verified/confirmed by medical professionals. This meant that health professionals’ beliefs and actions had a considerable impact in shaping sufferers experiences and future.

Sufferers whose pain persisted despite trying several different treatment options, eventually lost confidence in the conventional medical system and questioned the knowledge and competence of ‘so-called experts’. Many disparaging remarks were made about health professionals relating to their lack of clinical knowledge about RSI and their lack of sensitivity in communicating with sufferers. Either at the same time or more often after exhausting conventional medical treatment options, sufferers sought the help of alternative and complementary therapy practitioners such as osteopaths, acupuncturists, and Alexander Technique teachers.

#### *8.11.5.8 Summary of what a diagnosis means*

In summary, sufferers saw a diagnosis as the basis from which to find effective treatment, to eliminate any more serious underlying problem, as a means of accessing benefits (such as the benefits attached to the sick role e.g. sickness benefits and work place changes). In a few cases it was seen as vital medical evidence to support the sufferer’s legal compensation claim. Finally the diagnosis

provided a social label which they could use to negotiate their social identity and acceptance with others. Sufferers' medical validation of their condition by health professionals, (or conversely, its denial) had important consequences for other aspects of their lives since it potentially allowed access to both tangible and intangible benefits such as sickness leave, financial support and empathy. Much of RSI sufferers' experience was related to the legitimacy of their symptoms and condition.

#### **8.11.6 Overarching theme 3: Interference with social roles/functioning**

##### **Sub themes:**

- Interference with activity performance
- Impact of disability on social identity as an employee/worker/wife/husband/student
- General impact on self of no longer being a competent performer
- Being selective in social participation – withdrawing from some but opening up to others on the net leading to contraction/expansion of contacts
- Redistribution of domestic roles and work
- Impact of illness on domestic and work relationships
- Issues relating to legal aspects of RSI in the workplace

##### *8.11.6.1 Interference with activity performance*

RSI had the potential to interfere with many of sufferers' routine daily activities from their ability to engage in paid work to participating and contributing to family life and social and leisure pursuits. RSI also had the potential to restrict sufferers' lives by making them less mobile or less able or willing to drive. RSI could curtail freedom previously enjoyed and restrict their world of social contacts. Sufferers viewed the pain which accompanied RSI as an impediment to the things they wanted and needed to do such as work, leisure activities and personal relationships.

On developing RSI, sufferers' normal daily routines suddenly took on new dimensions whereby activities previously undertaken easily and automatically suddenly became deliberate and could no longer be taken for granted; weak muscles and loss of motor control made even lifting up a cup of coffee problematic. Sufferers became frustrated when they experienced difficulty lifting and holding things and felt embarrassed at frequently dropping things from their hands. Basic self-grooming activities such as washing hair became problematic since arms became fatigued when raised above the head, resulting in hair being washed less thoroughly than before. Brushing hair, tying hair back in a ponytail, applying make up or inserting contact lenses all became painful. Fastening buttons and zips either became difficult or could not be done at all. Some sufferers felt helpless because they were unable to maintain their physical appearance as before and felt they looked a mess.

Activities taken for granted such as holding open large books when reading, operating the buttons on a TV remote control, lifting up an iron or tidying up became difficult and frustrating. Sufferers were forced either to stop driving or to cut down their car use due to the pain and because they no longer felt safe driving due to their weakness and the side effects of the drugs taken to cope with pain.

#### *8.11.6.2 Impact of disability on self and identity*

The findings from the e-mail data highlighted very clearly the impact of RSI on work related activities and hence its impact on sufferers' identity as a worker but non work aspects such as parenting roles did not come across as strongly as in the focus group data. Negative aspects of work on their identity resulted from job loss, loss of earnings, being unable to perform as well as others, having to assume lighter duties and feeling that others thought they were skiving.

#### *8.11.6.3 Consequences of being disbelieved and doubted*

RSI sufferers were disbelieved about their symptoms because they were not given a medical diagnosis. This left them open to suspicion, doubt, and having their

experiences discredited and their integrity questioned. The longer this pre diagnosis state of diagnostic limbo continued, the more desperate sufferers became and the less confidence they had in medical professionals to provide explanations for the cause of their suffering or to provide them with pain relief. RSI sufferers' experiences of being in pain but without medical corroboration to support this, forced them into a separate world where their thoughts and actions became dominated by pain. Sufferers worried about their job security and livelihood and their sense of who they were became confused, and they worried about what others thought of them. As a result of RSI, some sufferers developed low self-esteem and lost confidence due to feeling they were less able members of society and less valued because of this reduced capacity to function as before.

#### *8.11.6.4 Social acceptance of RSI (symbolic significance)*

In addition to understanding and making sense of undesirable and painful symptoms, sufferers found themselves continually having to manage their social identity in ways to gain acceptance from others. Sufferers found this an emotionally draining process since outwardly sufferers appeared perfectly "normal" and "healthy" to others, which meant continually having to explain their condition. The doubt and suspicion which surrounded their condition had a devastating effect on their self-identify since they felt their integrity was being publicly challenged and therefore had to be constantly defended. The emotional toil this carried was seen in changes in personality where sufferers changed from being outgoing and sociable to being withdrawn and rejecting the company of others.

Sufferers had to understand, accept, accommodate and manage complex, unpredictable although ubiquitous painful symptoms as well as to convince those around them of the authenticity of their suffering. Media hype regarding the potential gains from legal compensation and lack of social awareness exacerbated their suffering by fuelling suspicion and arousing hostile reactions from work colleagues, health professionals and others.

#### *8.11.6.5 Invisibility of RSI creates doubt in the mind of others*

The confused social image of RSI as a medically and legally contested condition provided an additional burden for sufferers to contend with. Its ambiguous status meant RSI was accepted by some stakeholders but rejected by others due to divided medical opinion. The impact of this uncertainty for sufferers was that in the absence of any objective proof of their suffering, they felt obliged to “prove” their pain by convincing others of the authenticity of their suffering in order to defend their own integrity and self-image. Sufferers used visible symbols of pain, such as plastic hand splints or support bandages to ease discomfort, serve as a visible reminder to prevent them from “overdoing things” which might exacerbate their pain and to alert and convince colleagues that there was something “properly” wrong with them.

When no medical evidence was found long term, sufferers began to doubt their own sanity and considered the possibility of truth in the theory that RSI had a psychological basis. Generally however, sufferers were adamant that their pain sensations were genuine but were completely baffled why these could not be detected by the endless stream of examinations and tests they endured in the hope of finding a physical explanation for their symptoms.

Sufferers were hurt and distressed at the perceived implicit and explicit accusations regarding the legitimacy of their pain made by some health professionals. Sufferers believed that their body needed a rest away from work to avoid the actions which were causing or exacerbating RSI. When doctors refused to issue a sick note to RSI sufferers, denying them the opportunity for this much needed rest, they didn’t know who else to turn to and wondered if other health professionals such as a physiotherapist, osteopath, chiropractor or another recognised alternative practitioner, had the authority to recommend work place changes.

#### *8.11.6.6 Reconciling being ill and looking healthy*

Despite feeling emotionally drained from dealing with continuous pain and feeling physically exhausted from coping with the demands of paid work, daily life, and disrupted sleep, many outwardly appeared to be in perfectly good health. Sufferers’

appearance of being in good physical health conveyed a conflicting message to others who noticed discrepancies between their claims of being in pain and their healthy physical appearance. Not looking ill enough or looking too healthy raised doubts about their claims of being ill, as they failed to satisfy other people's expectations of what they should look like in order to qualify as being ill. Comments regarding how well they looked made by those around them were interpreted as implicit accusations of lying. At times sufferers even wished that they appeared more ill, as this would more accurately reflect the way they actually felt. Sufferers felt let down by their body which appeared to contradict their claims of illness rather than supporting them.

Sufferers felt they failed to meet society's expectations of a disabled person because they didn't physically look any different from others, and did not display any visible clues to indicate their disability. Sufferers felt that more sympathy was accorded those with some visible markers to alert others of their disability such as a guide dog, or a white cane, indicative of blindness or partial sightedness or those who wore a hearing aid. Sufferers found it hard to convey fully to employers, medical professionals, government benefit agencies and others, the very debilitating nature of RSI where the accomplishment of even basic tasks such as lifting a cup of coffee presented them with a major challenge, leading others to think they were exaggerating their claims about how RSI affected them.

## **8.12 Summary of e-mail findings and discussion**

The RSI experience was dominated by a search for a medical explanation and legitimacy with the expectation that their painful symptoms would be medically confirmed and effectively treated. When this ideal failed to materialise, sufferers' focus changed to wanting to be believed and socially accepted by others.

The medical encounters of sufferers with non specific RSI were particularly difficult because sufferers had to contend with invisible painful symptoms which impeded or restricted their daily life routines but which were disbelieved by others including health professionals resulting in sufferers being denied access to sick role benefits and positioned them in a socially difficult situation in which they were neither well nor socially designated sick.



Having RSI pervaded all aspects of sufferers' lives from their ability to earn a living to changing their self identity and sense of self worth. Implicit and explicit accusations of malingering threatened sufferers' moral integrity together with changed physical and mental capabilities which had considerable consequences for their sense of identity, diminished their self confidence and self esteem and created emotional upheaval.

Sufferers found pain confusing, unpredictable and noticed that pain intensity often did not correlate with the level of activity undertaken. Pain changed in intensity, both within and between individuals as well as its bodily location. Treatments were largely ineffective and sufferers resorted to using orthodox and complementary therapies in tandem.

To cope with the enormous changes resulting from having RSI, sufferers needed support and understanding from different social groups including employers, health professionals and close social networks comprising family and friends. However, genuine and continuing support was often difficult to obtain. Adjustments were made to social networks such that whilst some social relationships were curtailed, other social networks were expanded in a different direction, such as online support group networks. For these sufferers, the support group became a highly valued source of information and support in an environment where others believed them, could relate to them through a shared experience of RSI and pain and therefore understood their concerns.

**Table 8.3: Topics identified from e-mail study**

<p><b>THEORETICALLY DERIVED CHRONIC PAIN FRAMEWORK INITIALLY APPLIED TO DATA</b></p> <p>(Morley et al., 1999)</p> <p>Pain</p> <p>Cognitive appraisal/ coping/</p> <p>Pain</p> <p>Behaviour</p> <p>Mood/affect</p> <p>Social role functioning</p> <p>Health care usage</p> <p>Biological functioning</p> <p><b>FRAMEWORK EXPANDED TO INCLUDE:</b></p> <p>Financial/legal aspects</p> <p>Key stakeholders in RSI</p>	<p><b>Main experiences from e-mail data</b></p> <p><b>PERSONAL COPING</b></p> <p>managing symptoms</p> <p>becoming an expert - searching for information from range of sources</p> <p>Support group is a life line</p> <p>Importance of support from employer, family and health professionals</p> <p>Thinking differently and taking a different approach to doing things</p> <p>Making decisions/choices</p> <p>Variable success in coping</p> <p>Dealing with emotional aspects of illness</p> <p>Attribution and explanations for RSI</p> <p><b>HEALTH CARE EXPERIENCES</b></p> <p>Diagnosis process difficult</p> <p>(Long or no diagnostic closure reached, misdiagnosis, negative tests)</p> <p>Doctors perceived as dismissive don't listen, don't believe in RSI</p> <p>Treatment generally ineffective</p> <p>Both traditional and complementary therapies used</p> <p><b>SOCIAL ROLE FUNCTIONING</b></p> <p>Importance of work and finding ways to continue working despite pain</p> <p>Reduced social participation</p> <p>Changes in domestic situation</p> <p>Ability 'to do' things affected</p> <p>Impact on identity and self</p> <p>Relationships affected (work, home, social)</p> <p>Legal aspects of RSI in workplace</p>	<p><b>Main topics identified from e-mails for further exploration in focus groups:</b></p> <p>Understand how people with RSI illness and disability manage in their daily lives</p> <p>Gain deeper Understanding of sufferers' health care experiences, particularly diagnosis issues and the nature of their medical encounters</p> <p>Understand the impact of RSI on sufferers' social role functioning, particularly its impact on work and other social roles and relationships</p>
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### 8.12.1 Topics identified for further exploration in focus groups

From the e-mail data the three key areas identified as warranting further exploration in the focus groups were: how individuals coped with RSI illness and disability, their health care experiences particularly the problematic process of obtaining a diagnosis and medical encounters, and how having RSI interfered with their social role functioning both in and outside of work, and relationships.

<b>Theme No</b>	<b>Main Theme Name</b>	<b>Sub themes supporting main theme</b>
1	<b>Personal coping</b>	<ul style="list-style-type: none"><li>• Recognising onset</li><li>• Interpreting symptoms</li><li>• Formulating explanations for RSI</li><li>• Motivation to seek medical help</li><li>• Importance of support in RSI – stakeholders</li><li>• Strategies to manage RSI</li><li>• Information seeking</li><li>• Stages and extents of coping</li></ul>
2	<b>Medical help seeking experiences and significance of a diagnosis</b>	<ul style="list-style-type: none"><li>• Variability in treatment and knowledge of RSI</li><li>• The centrality and meaning of a diagnosis</li><li>• Legitimacy issues (invisibility, looking healthy)</li><li>• Reasons for a problematic diagnosis</li><li>• Negative doctor/patient encounters</li><li>• Ineffectiveness of treatments</li><li>• Use of both traditional and complementary therapies</li></ul>
3	<b>Interference with social roles</b>	<ul style="list-style-type: none"><li>• Interference with performing routine activities</li><li>• Impact of disability on social identities e.g. worker, husband/wife, student, parent</li><li>• Impact on self as a less able/competent performer impact of being unable to meet expectations of self and others</li><li>• Selective socialising- withdrawing from some people but expanding network of online friends/contacts</li><li>• Redistribution/changes in domestic work and roles</li><li>• Impact of illness on relationships (family, friend, work colleagues, wider social networks)</li></ul>

**Table 8.2 Conceptualisation of the RSI experience following re-analysis of e-mails**

As mentioned earlier, analysis is an iterative process. In this study the researcher having carried out an initial analysis to determine the topics to which most people contributed to, returned to the original e-mail data and re-analysed it again after the focus group interviews had been analysed. This allowed the e-mail data to be re-visited in the light of themes which had emerged from the focus groups.

## **9 Chapter 9 Phase 2: Online focus groups**

### **9.1 Introduction**

The previous chapter covered the methods and findings from the e-mail study. This chapter now builds on the earlier e-mail study findings by taking further some of the issues identified as warranting further exploration in the second stage of this study, asynchronous online focus groups. For readers' convenience, the methods, findings and discussion for the focus group study have been presented together in this chapter. This chapter covers sampling and recruitment, ethical procedures, development of the research site and insights gained from a pilot online focus-group study. It also includes justification for the selection of asynchronous over synchronous groups, sample and group size, number of focus groups and duration of focus groups. Finally, the data analysis and findings are presented.

The aims of this part of the study were to:

1. Explore in more depth areas identified as important aspects of the RSI experience in terms of what sufferers think, feel and do to make sense of RSI, through capitalising on group interactions
2. Assess the utility of the online methods used to access sufferers' experiences of RSI

### **9.2 Rationale for online focus group study**

As discussed earlier in the methodology chapter, focus groups have become a well established and versatile form of group interview increasingly used in health care research to generate rich descriptive responses (Bloor et al, 2001; Barbour and

Kitzinger, 1999; Morgan, 1997; Krueger and Casey, 2000). The 'hallmark' feature of focus groups is their ability to provide insights into people's experiences through their group interactions, which cannot be accessed through any other method (Kitzinger, 1994; Morgan, 1997). This versatile method has been developed further because of advances in computer technology (Krueger, 1995; Kenny, 2005; Stewart and Williams, 2005). The internet presents researchers with unprecedented opportunities to recruit and engage participants in online research (Sharf, 1999). Moreover, Bloor et al, (2001) stated that virtual focus groups were well suited for individuals who were already familiar with this form of communication. Since members in this study were recruited from an online support group and were already familiar with and used electronic communication to communicate their RSI experiences to others, this seemed a logical way to access and understand their experiences.

In this study, online focus groups are considered to be a variation of a pre existing method rather than a new and separate method, in agreement with Bloor et al, (2001). Several options were explored for communicating electronically with research participants both from the literature and consulting experts in the field (Stewart and Williams, 2005; Jones, 1999; Mann and Stewart, 2000). Following a review of these and taking into account resources already available in the University, the idea was conceived of developing an online research venue in which focus groups could be conducted in privacy. This method also provided a way of recruiting participants from a non-clinical setting.

### **9.3 Ethical approval and informed consent**

As discussed in the previous chapter ethical approval for the study was obtained from Queen Margaret University Ethics Committee.

Prior to participation in the study, a consent form was sent to each participant by e-mail. The consent form was based on the standard paper version of the University consent form, but was sent and received electronically. Participants were asked to read the electronic form, and if they understood and were satisfied with the terms of

their involvement, they were asked to add their name to the form and return it to the researcher. A similar electronic consent form procedure was used by Dr Kate Stewart (formerly Robson) (private communication) and Lenert et al, (2002). The researcher logged all the electronic forms. Two individuals signed and sent paper copies to the researcher at the University. Participants were also asked to complete an electronic form with personal demographic information to help provide some definition of the group for data interpretation, but not all participants returned this (see demographic data in tables 9.1 to 9.5).

## **9.4 Focus group pilot study**

A pilot study was conducted to acquire practical experience in running online focus groups and to test the clarity of the 'log on' instructions which would guide lay members of the public to the study website. The pilot study ran for 10 days and included in total 6 participants (academics and PhD students) and the researcher.

The feedback received from the pilot study indicated that 10 days seemed about the right length of time for the study. In addition, it was noted that the researcher needed to:

- Lead discussions more ;
- Interact more with the participants to elicit responses;
- Explain clearly what was expected from participants;
- Provide regular summaries/updates for those who joined late or had missed part of the proceedings to enable them to 'catch up';
- Enlarge the size of the group to more than 7.

## **9.5 Development of the research site**

A private password protected site hosted on the University's main website was specifically created for this research as used in other online studies (Murray, 1997; Kenny, 2005; Lenert et al, 2002). The advantages of having a private site is that it ensures non-participants cannot just 'drop in' the site and no one can lurk; only

those given a password can access the site. However within the group context, anonymity was surrendered (as it would be in a face to face group) as the University had requested participants' names before allowing access. However, no private e-mail addresses were visible to anyone in the group.

As WebCT was a resource already available in this University it was decided to adapt this technology for research purposes. Valuable background for this stage was found in Mann and Stewart, (2000) and books by Salmon, (2000; 2002).

On line focus groups can be run in synchronous mode (real time or immediate where participants are co-present) or asynchronous mode (more like an e-mail response involving a delay between sending and receiving messages) (Mann and Stewart, 2000; Jones, 1999; Stewart and Williams, 2005). The asynchronous mode was selected in this study because it offered maximum flexibility allowing participants to contribute at their own convenience and was considered less intrusive (Salmon, 2000). It also resembled more closely communication used in the discussion list from which most of the participants were recruited. With the asynchronous mode, participants could access the site 24 hours a day for however long they wanted or needed to (Salmon, 2000). It was also considered that people with other commitments (e.g. work, children) may be more reluctant to commit themselves to participate only at a set time. In addition, since participants from other countries were also taking part, a synchronous group would have potentially been more difficult to organise because of the different time zones. The literature also indicated that synchronous groups were potentially more difficult to manage because of the faster pace of spontaneous discussions and difficulties convening everyone at the same time. Novice researchers were advised against using this mode (Stewart and Williams, 2005). Kenny, (2005) reported her unsuccessful attempt at running synchronous real time discussions on WebCT due to the difficulty in convening all participants.

The website design aimed to strike a balance between presenting a professional and credible image of the research project, using for example, the official Queen Margaret University crest to show its institutional affiliation, and keeping the site informal to encourage open discussions. In efforts to make the site friendlier, the researcher shared with participants some information about herself and posted a



colour photograph to allow participants to see the “human face” behind the e-mail messages (Madge and O’Connor, 2003).

Within the site a general welcome message was posted together with a re-statement of focus group aims and background details of the study. The first time each participant entered the site, the researcher extended a personal welcome to the individual (Salmon, 2000).

### **9.5.1 Access to the site**

WebCT software used in this study did not require participants to have any special software apart from a web browser such as Internet Explorer. Each participant was sent the University’s Universal Resource Locator (URL) and a password to access the site. The research site was accessed by participants in Australia (1), New Zealand (2), America (2), France (1) Switzerland (3) and UK (48). One UK participant also accessed the site from Iraq whilst visiting her husband during the study.

The site was opened prior to the start date for the study to enable participants to check that they could successfully log on and to become familiar with the technology beforehand (Salmon, 2000). Two people had problems accessing the site; of which one participant was unable to access the site and therefore did not participate in the study. During the running of the focus groups, the server went down twice which had a minor disruptive effect.

## **9.6 Online group interaction rapport, ambience and cohesiveness**

As discussed in the methodology chapter, online communication is different from face to face communication because speech, listening, observing body language, establishing eye contact, facial expressions such as giving encouraging smiles are all absent online (Sweet, 2001). To compensate for this lack of social cues (Stewart and Williams, 2005), extra effort was made to ‘get to know’ participants during the recruitment and organisation of the groups (Salmon, 2000).

## **9.7 Sampling and recruitment**

A purposive sampling strategy was used to access RSI sufferers (Coyne, 1997). The list owner introduced the researcher to the group after which the researcher made contact with list members to provide information about the study and to invite members to participate in the study or to contact her privately for further information. In total, 57 self-selected individuals with RSI (or recovered from RSI) participated in the groups consisting of 43 females and 14 males (approximately a 3:1 ratio).

### **9.7.1 Number of focus groups**

In this study five focus groups were run as several groups were considered to offer a broader range of beliefs and values within the study (Morse and Field, 1995). It also enabled comparisons to be made across the groups for homogeneity. Krueger and Casey, (2000) advised against running just one group since the observations made may be due to group dynamics and unrepresentative. It was also considered that smaller groups might facilitate easier discussions and be easier for the moderator to run.

### **9.7.2 Number of participants in each focus group**

As seen in the Methodology Chapter 7, the optimum number of participants in a face to face focus group is 6-8. For online teaching, Salmon, (2000) recommended groups of between 12 and 20. Murray, (1997) used 6-8 participants in online focus groups but felt more interaction would have resulted from a larger group. The pilot study indicated that higher numbers than 7 would be more effective in generating group interaction. However, this had to be balanced with ensuring moderation is not made too difficult for the researcher and to give everyone an opportunity to participate (Bloor et al, 2001). Based on these considerations, a compromise was sought of aiming to have about 12 individuals per group.

Potential participants were offered the choice of joining one of four groups to be run during May/June 2003. Participants in group 5 who were recruited through the RSI Association by telephone and e-mail were not given such options as only one such group was run.

### **9.7.3 Duration of focus groups**

Each group was run for 10 days. Whilst 90 minutes is the optimum time for the duration of face to face groups, asynchronous groups can continue for much longer periods (Bloor et al, 2001; Salmon, 2000). Feedback from the pilot study suggested that 10 days was about the right length of time for the study. The subsequent feedback from research study participants confirmed this. Since the e-mail study had already covered the breadth of RSI experiences, 10 days was considered sufficient to gain the depth sought.

### **9.7.4 Background to focus group participants**

Participants had diverse RSI diagnoses comprising both well defined clinical entities such as Tenosynovitis, Tendonitis, Carpal Tunnel Syndrome and de Quervain's disease and many cases of non specific diffuse arm pain/ RSI. It also included those who were still in the process of achieving a diagnosis, people who were currently working, unemployed due to RSI, currently on sick leave (long and short term and one retired sick), post graduate and undergraduate students and three individuals who were self-employed. One person had had a successful legal outcome and a very small number were pursuing a legal case. Participants covered a range of stages in the RSI cycle from two with RSI onset of just weeks to one individual who had had RSI for 25 years. The majority however were somewhere in-between with an average time of 5 years, 2 months. The educational level ranged from basic education to several in the group who had a higher degree although this information was not specifically asked for. The participants in this study were employed in a variety of occupations in different sectors including the IT industry (e.g. analysts, consultants, web and developers), the education sector (e.g. university lecturers, researchers, librarian, undergraduate and postgraduate students and teachers) and

the Health sector e.g. employees in the National Health Service (NHS). Many participants were engaged in administrative or secretarial work (e.g. in the Civil Service, universities and within companies) whilst others were musicians, worked in publishing or had managerial roles. Of the 57 participants, 39 were either married or living with someone, 12 were single, 3 were separated or divorced and 3 were unknown. The age in the groups ranged from 21 to 63. Demographic information about participants is provided in tables 9.1 to 9.5 below.

### **Descriptive statistics of focus group participants (n=57)**

Number of females	43
Number of males	14
Average age years	37 years, 6 months
Age range	21-63

#### Numbers of participants within each age category

20-29	14
30-39	16
40-49	15
50-59	6
60-69	1
Unknown =	5
Average duration of RSI (years)	5 years, 2 months
RSI duration range	1 month - 25 years

**Table 9.1 DEMOGRAPHIC DATA FOR FOCUS GROUP 1**

Participant number	Sex	Age	Marital status	Employment status	RSI Duration	Country
P001	F	54	Married	Off work sick	2 years 10 months	UK
P002	F	36	Married	Employed full time	22 years	UK
P003	F	28	Living with someone	Employed full time	2 years 1 month	UK
P004	F	23	Single	Employed full time	6 months	UK
P005	F	23	Single	Unemployed	11 months	UK
P006	F	29	Separated/ Married	Employed part time	5 years 9 months	UK
P007	M	23	Single	Employed full time	3 years	UK
P008	F	45	Married	Employed full time	25 years	UK

Participant number	Sex	Age	Marital status	Employment status	RSI Duration	Country
P009	F	32	Single	Employed full time	15 years 5 months	UK
P0010	M	31	Living with someone	Employed	2 years	USA
P0011	F	40	Married	Employed part time	7 years 5 months	UK
P0012	F	38	Married	Employed	3years 5 months	UK

*Focus Group 1: Average age=33years 6 months; Average duration of RS=7yrs 6 months*

**Table 9.2 DEMOGRAPHIC DATA FOR FOCUS GROUP 2**

Participant number	Sex	Age	Marital status	Employment status	RSI duration	Country
P0013	F	57	Married	Other	2 years	UK
P0014	F	53	Married	Off work sick	5 years 10 months	UK
P0015	M	22	Single	Student	1 year	FRANCE
P0016	M	44	Single	Self employed	3 years	USA
P0017	F	30	Married	Unemployed	2 years 11 months	UK
P0018	F	44	Living with someone	Employed full time	2 years 3 months	UK
P0019	F	30	Married	Employed full time	8 months	SWITZERLAND
P0020	F	22	Single	Employed full time	10 years 6 months	UK
P0021	F	44	Living with someone	Employed full time	5 years 1 month	UK
P0022	M	37	Married	Employed full time	4 years 10 months	UK
P0023	F	28	Living with someone	Student	2 years 11 months	UK
P0024	M	49	Married	Employed full time	2 months	UK
P0025	F	39	Living with someone	Employed full time	9 years 10 months	UK

*Focus Group 2: Average age=38 years 5 months, Average duration of RSI=3 years 11 months*

**Table 9.3 DEMOGRAPHIC DATA FOR FOCUS GROUP 3**

Participant number	Sex	Age	Marital status	Employment status	RSI duration	Country
P0026	F	63	Married	Employed full time	11 years 9 months	NZ
P0027	F	51	Married	Employed part time	3 years 6 months	UK
P0028	M	46	Married	Off work sick	7 years	UK
P0029	F	39	Living with someone	Off work sick	4 years 10 months	UK
P0030	M	44	Living with someone	Employed part time	1 year 9 months	UK
P0031	F	35	Single	Employed full time	6years 9 months	UK
P0032	F	35	Married	Employed full time	3 years 1 months	UK

Participant number	Sex	Age	Marital status	Employment status	RSI duration	Country
P003	F	46	Divorced	Employed full time	3years 11months	UK
P0034	F	21	Living with someone	Student	1year 1month	UK
P0035	F	29	Single	Student	1year 10 months	SWITZER LAND
P0036	M	N/A	N/A	Employed	N/A	UK
P0037	F	N/A	N/A	N/A	N/A	AUSTRALIA

*Focus Group 3: Average age= 40 years 11 months, Average duration of RSI= 4 years 6 months*

**Table 9.4 DEMOGRAPHIC DATA FOR FOCUS GROUP 4**

Participant number	Sex	Age	Marital status	Employment status	RSI duration	Country
P0038	F	31	Living with someone	Employed full time	4 months	UK
P0039	F	40	Married	Student	6 years	NZ
P0040	M	25	Single	Employed full time	1 year 1 month	UK
P0041	M	28	Single	Employed part time	3 years 8 months	UK
P0042	F	N/A	N/A	N/A	N/A	UK
P0043	F	27	Single	Employed full time	1 month	UK
P0044	M	50	Married	Self employed	10 years	UK
P0045	M	48	Married	Employed full time	2 years 7 months	UK
P0046	F	31	Living with someone	Employed full time	4 years	UK
P0047	F	28	N/A	N/A	N/A	UK
P0048	F	30	N/A	N/A	2 years 5 months	UK

*Focus Group 4: Average age= 33 years, 10 months; Average duration of RSI= 3 years 4 months*

**Table 9.5 DEMOGRAPHIC DATA FOR FOCUS GROUP 5**

Participant number	Sex	Age	Marital status	Employment status	Time with RSI symptoms	Country
P0049	F	34	Married	Employed part time	1 year 11 months	UK
P0050	F	44	Married	On sick leave	18 years 5 months	UK
P0051	F	47	Married	On sick leave	3 years	UK
P0052	F	49	Married	Self employed	5 years 9 months	UK
P0053	M	34	Married	Employed full time	2 years 11 months	UK
P0054	F	55	Married	Retired Sick	12 years 11 months	UK
P0055	F	N/A	Married	N/A	N/A	UK
P0056	F	40	Married	Not working	3 years 8 months	SWITZ

Participant number	Sex	Age	Marital status	Employment status	Time with RSI symptoms	Country
				through choice		ERLAND
P0057	F	N/A	N/A	N/A	5 years	UK

*Focus Group 5: Average age = 43 years, 4 months, Average duration of RSI = 6 years, 8 months*

The level of interaction in the groups varied as indicated by the number of postings made by the groups with group 4 appearing less communicative than the other four groups.

#### **Postings made in the five focus groups**

Focus group	Number of participants	Total number of postings made in the group
<b>1</b>	<b>12</b>	<b>172</b>
<b>2</b>	<b>13</b>	<b>144</b>
<b>3</b>	<b>12</b>	<b>191</b>
<b>4</b>	<b>11</b>	<b>70</b>
<b>5*recruited through the RSI Association</b>	<b>9</b>	<b>125</b>

An average of 140 e-mails was posted per group. Of these the researcher posted on average 23 e-mails per group (including welcome messages). Salmon, (2000) suggested moderator e-mails should not exceed 1 in 4.

## **9.8 Topic schedule used during online focus groups**

A very broad topic schedule was used during the focus groups based on what appeared to be this group's key concerns as identified in the preceding e-mail analysis phase of the study. The aims were to gain more depth into these areas to supplement the breadth gained in the e-mail study. The three main areas to which most people contributed postings in the e-mail study discussion list were found to be

related to their health care experiences, the impact of RSI on their social role functioning, particularly paid work and the strategies people used to cope with and manage RSI. Whilst pain was important, it was usually considered in terms of how it was managed in the clinical setting or how it interfered with their activities. In advance of the study, each participant was asked to prepare a written account of their RSI experience which they would post at the start of the study. The aim of this was two-fold; to avoid participants from being influenced by what others had written and also as a way of building rapport within the group by providing information of interest to other sufferers. It was also hoped that this would stimulate further questions. Furthermore it would provide a more complete account of people's experiences than it was possible to obtain through the discussion list. In the focus groups participants were encouraged to talk about what was important to them and to open up new areas of discussion of interest/concern to them.

## **9.9 Analysis of focus group interviews: introduction**

The analysis of focus group transcripts differs from other forms of data analysis since its focus is on interaction to gain additional insights into people's experiences (Morgan, 1997; Barbour and Kitzinger, 1999). In making group interaction central to the analysis, the researcher is obliged to actively consider group dynamics which can yield valuable information about the context in which data was generated and insights into people's negotiations of social reality, which might otherwise not be noticed (Cattarell and McLaren, 1997; Stevens, 1996). This includes details about the ambience and interaction within each group and the level of rapport which existed between the participants and the researcher. Therefore, in this study focus group analysis was undertaken at two levels; an analysis of group interaction, which is the hallmark feature of focus groups, and an analysis of the substantive content of the data relating to the RSI experience. To help focus on interaction, a set of questions produced by Stevens, (1996) was used to guide this aspect of the analysis.



### **9.9.1 Questions to help focus on group interaction**

To draw attention to interaction in face to face focus groups, Stevens, (1996) suggested researchers' used the following questions to help direct attention to group interaction.

- What common experiences were expressed?
- What questions did participants ask?
- How did participants compare their experiences with others?
- What did participants agree and disagree on?
- What are the controversies/contradictions in the group?
- How do participants interact with and influence each other online?
- How were emotions expressed and handled online?
- Was a particular member or viewpoint dominant or suppressed?
- What level of group cohesiveness was attained?
- What was the relationship between the researcher and participants?

The value of Stevens' (1996) schema of questions was that they helped focus on group dynamics as well as on the substantive data and drew attention to issues of candour, conformity and censorship.

### **9.9.2 Unit of analysis**

The basic unit of analysis in the focus group study was the whole group rather than individuals, since the aim was to find the 'essence' of the RSI experience (Frey and Fontana, 1991). However, data was analysed both on a 'within case' basis (i.e. individual stories/case histories and contributions) and cross the five groups to draw comparisons in order to arrive at an overall essence of the RSI experience. This process helped explore data in different ways.

### **9.9.3 Initial observations made during the groups**

It was noticed early on that events in the group appeared to be unfolding on a daily basis during the 10 day period with participants promising to report back on happenings which had occurred earlier in the day. Examples included one person reporting back after a visit to his GP whilst another reported on what happened on her first day back at work following sick leave. It was also noticed (and stated by participants) that individuals were very interested in reading each others' experiences about RSI, often identifying commonalities and occasionally differences in their experiences.

## **9.10 Analysis of focus group data**

Focus group transcripts were copied and transferred from the WebCT research site into word files. Each line of the transcript was numbered and the heading of each message posted was identified as a separate unit to enable text to be cross-referenced to its author when data was later disassembled. The full text from each focus group was read in paper format to become more familiar with the experiences and issues discussed. Attention was also paid to who contributed to discussions and the nature, form, number and length of e-mails posted. Also considered were the group dynamics regarding how individuals related to each other and the researcher.

Following familiarisation with the depth and breadth of data collected, the data from Group 1 was then read and re-read actively several times, noting any recurring patterns of events or comments, commonalities and differences in experiences and any striking or unusual occurrences. Notes also continued to be made on group interaction keeping in mind Steven's (1996) schema of questions.

This detailed analysis of Group 1 data involved disassembling the data into an initial set of around 70 codes representing data observations (Charmaz, 1983). Simultaneously, another experienced qualitative researcher not directly involved in the project, also read and coded part of the data from Group 1. The codes devised by both researchers were then compared and discussed and generally found to be

very similar. Next, a full list of codes was produced with efforts made to eliminate overlapping categories and to refine the codes by changing code descriptions or re-coding material. This initial set of codes was then applied across another group to test if the data in the next group could also be accommodated within this coding structure. Where this was not possible, the coding structure was modified to accommodate the different data. This was repeated with each group until the data from all five groups could be accommodated within the framework. Similarities were then sought in the sub codes to relate codes. For example the descriptive code 'healthcare experiences' related to many sub codes such as medication which in turn is based on many different aspects of medication. Participants discussed the type of medication used (or avoided) e.g. anti-inflammatory drugs, amitriptyline, drug side effects, their efficacy, people's beliefs about medication, the range of medications tried such as complementary, prescription drugs, over the counter medication. In this way the large amount of data was gradually reduced in preparation for interpretation and abstraction.

Particular attention was paid to the analysis of Group 5, since this group had deliberately been recruited from a source other than the online support group to provide some comparison between their experiences of RSI with participants recruited from the online support group. Group 5 was recruited through the RSI Association.

Next, comparisons were made across all five groups to search for the predominant recurring patterns/themes/issues whilst simultaneously remaining sensitive to deviant/ unusual cases. In one of the groups for example, a female was interested in others' views on personality and RSI. In another group, a man used the research as an opportunity to recount in detail his RSI history, based on a diary he had kept for the five years prior to the study. His story charted his journey in five stages which he described as first getting RSI, struggling through it, making recovery and coming out, reflecting on the past and intentions for the future. Such 'serendipitous findings' were considered alongside the more general discussions. The initial 70 codes were then gradually reduced by aggregating these detailed codes into broader themes. Through this process 10 main areas related to sufferers' experience emerged which all related to changes RSI sufferers confronted or had to make.

## **9.11 Findings from focus group interactions**

As stated earlier, the nature of interaction online is changed from face to face groups since no one is physically present during online focus groups and normal social cues such as visual and aural are absent (Stewart and Williams, 2005; Salmon, 2000).

To compensate for this, a keyboard paralanguage has been developed which enables nuances in meaning to be expressed using a keyboard and a computer screen (Murray and Sixsmith, 1998; Stewart and Williams, 2005). In this study, many examples of the use of this paralanguage were seen such as emoticons (smileys), capitalisation and the use of expressions normally associated with spoken communication such as ouch!, Yuk, ugh! Hmm. Overall the interaction between participants in the focus groups in this study was generally friendly but this may have been influenced by the researcher stating this as an aim at the outset and the nature of the discussion topic was one which brought sufferers together and was something they were willing to talk about. However, the expression of emotions such as anger was still apparent and seen in the use of strong language, capitalisation and use of asterisks. Members also felt relaxed enough in the groups to use moderately strong language and expressions such as 'crap', 'bastard', etc. This information provides insights into the emotional tone of discussions in the group. Referring to others by name and offering cyber hugs as emotional support were other useful indicators of the level of group cohesion. Group members asked each other questions, were often in agreement with comments made by others and felt free to add their own perspectives to others' comments. Some threading was evident in e-mails where two or more people engaged in e-mail exchanges.

Of the five groups run, only one of the groups, Group 4 appeared to have been less well developed in terms of cohesiveness. This group generated only half the number of e-mails as the other groups despite similar numbers in the group. This could partly have been explained by insufficient time for this group to build a high level of rapport and also possibly due to difficulty accessing the technology. One individual stated part-way through that he had not understood properly how the system worked and as a result had not realised that e-mails had been sent to him which he had not

responded to. A further explanation was that this group seemed to focus on the technical aspects of using computers in the workplace rather than personal issues.

### **9.11.1 Overall conceptualisation of focus group data**

The following broad themes were developed from aggregating codes from the microanalysis stage. The data was reduced to 10 broad themes covering different aspects of sufferers' experiences. These 10 themes were then collectively used to conceptualise the overall RSI experience as being one of 'change'; based on the manifold changes individuals with RSI faced and had to make.

The experience of RSI sufferers involved in this study was complex, often spanning several years and involving manifold changes both at a personal and at a wider social level for both individuals and their families. This chapter discusses the data from the focus group discussions, leading to identification of a number of themes and sub-themes. It then brings the themes together to show how an overall conceptualisation was developed. Although these themes have been presented here as discrete themes, in the reality of sufferers' experiences it is difficult to disentangle them and there are therefore necessarily areas of overlap. These themes are now discussed in detail to show how this overall conceptualisation of change was developed. The concept of 'change' emerged as a prism through which to view the overall RSI experience from focus group data. This conceptualisation of 'change' is considered a useful and more neutral term than the predominantly negative previous conceptualisations of illness as loss, restriction or limitation. While having RSI was undoubtedly associated with considerable loss and restriction, the concept of change allows positive elements of their experience to emerge alongside adverse consequences. The concept of change allowed the many underlying features of their experience to be brought together and captures the many changes they had to confront and make in response to RSI. These changes were evident in their everyday lives, identities and relationships. Changes occurred in how they viewed themselves in a society where self worth is closely tied with the ability 'to do' things, and in the light of these changes, how others viewed them. These changes could be profound or minimal, could be in their financial circumstances, in their employability, in their social life or in simple routine activities such as shopping.

From whichever perspective it is viewed, RSI had the potential to change all aspects of their lives and the concept of change provides a means of understanding how these changes contribute to the experience of RSI. Viewing the RSI experience from the point of view of change has important implications for the management of the condition at a medical as well as a personal level. An overview of this conceptualisation of change is provided diagrammatically in Figure 9.1. A full table of themes and sub themes is also provided at the end of this chapter.

### **9.11.2 Use of illustrative quotes**

The aims of this second phase of the study were to explore in more depth the experience of RSI from the sufferer's perspective using internet based focus groups to build on the sensitising concepts developed from the earlier e-mail analysis. In this study whilst the essence of sufferers' experience was sought through focus group interaction, it was recognised that each participant's experience was unique and efforts have therefore been made here to present both the commonalities in sufferers' RSI experiences together with some of the exceptional events and cases. Illustrative quotes and the researcher's interpretation of them are presented in this chapter to substantiate or clarify the key themes developed. These particular quotes were selected on their ability to illustrate well either a common or an exceptional facet of their experience. However, due to wordage restrictions, the use of quotes has been kept minimal, but offer readers some direct access to sufferers' own words to enable readers to form judgments about how the data has been interpreted. Each quote is labeled with an identifying code which is cross-referenced to the respondent's profile in the figures provided earlier in this chapter.

## **9.12 Main theme 1: RSI onset, symptoms and explanations**

### **9.12.1 Sub theme: RSI onset**

The early experience of RSI often involved noticing changes in the body which subsequently led to changes in sufferers from being a person with occasional aches and pains to becoming a person with something perceived as more serious and

which required medical investigation. The process of becoming ill in RSI often occurred on a gradual basis, but equally in other cases it could be quite sudden. Regardless of the manner or speed of onset, RSI was usually unexpected by the sufferer and viewed as something that happened to others. Sufferers interpreted the symptoms experienced (primarily pain) as signalling some biomedical malfunctioning, but most were unaware of what the problem was, with many claiming no knowledge of RSI prior to getting it. However in a few cases, another family member (parent, grandparent, sister, brother) had experienced a similar illness which alerted these individuals to the possibility of RSI. In response to pain and discomfort, sufferers initially opted to either do nothing, preferring to wait and see how symptoms progressed with time, or to self manage them with the underlying hope they would eventually disappear of their own accord. Pain symptoms were often normalised (made 'routine' or 'ordinary' in efforts to reduce their disruptive effect, Charmaz, 2003) by attributing them to factors such as a high workload, and as a consequence, the inevitability of some associated discomfort.

In this study, it was when the pain persisted despite overnight and weekend rest that eventually motivated sufferers to seek medical help. Background symptoms may have existed for weeks, months or even years and tolerated prior to seeking help since previously symptoms had abated following rest. When symptoms no longer responded to rest, a threshold of tolerance was exceeded and sufferers were no longer prepared to 'do nothing,' and perceived their symptoms as signifying something more serious.

#### **9.12.2 Sub theme: Enigmatic nature of RSI symptoms**

Sufferers' pain symptoms were enigmatic and defied explanation, prediction or logic. Typical symptoms people described included aches and pains, shooting pains, pins and needles, discomfort, sleep disruption, exhaustion, weakness, sensations of swelling, muscle tension, burning sensations and occasionally a cold sensation in the arm. The anatomical location of the pain whilst usually in the hand, arm, wrist, shoulder, neck or back, could spread to other parts of the body or change location. Moreover pain symptoms could be recalcitrant persisting for months, years and decades like other chronic pain conditions. These symptoms were discussed earlier

in the chapter on pain. One sufferer described keeping an 'RSI diary' in which she had intended to record her pains to help her explain them more clearly to doctors. However, she abandoned the idea after only a week because everyday she experienced different pains in different places with no discernable patterns. Insights into the unpredictable and confusing nature of pain are captured in the following comment:

Participant P0010: 31 year old male with RSI for 2 years (Group 1)

*"Apart from being thoroughly bemused by this [unexplainable pain], it keeps me on the emotional rollercoaster that life has become just when I think I'm getting better, or coming out of an episode I have a bad day and I can't explain it. In addition to this is trying to explain it to those around you."*

There appeared to be little correlation between the intensity and severity of pain felt and the amount or level of activity undertaken. Pain could fluctuate from being all consuming to being virtually absent and varied between individuals and even within the same individuals at different times. Within the study, sufferers recognised whilst they shared many common experiences, pain was also unique to each person and what 'worked' for one individual, would not necessarily work for another, forcing each person to seek an individual solution, usually through a process of trial and error. Since the locus of pain was the hands, arms, wrist, neck and back and determined what activities could or could not be undertaken, there was a greater awareness of both the body in general and of these particular parts of the body. This heightened consciousness of the body in illness is well recognised in the literature (Leder, 1990; Idler, 1979; Bendelow and Williams, 1996; Eccleston and Crombez, 1999; van Manen, 1998).

### **9.12.3 Communicating pain**

This uniqueness of the way pain is experienced in RSI together with personal difficulty in understanding and managing it, created a barrier in communicating their experiences to others. As seen in Chapter 2 on pain, this difficulty in communicating pain is well documented through the writings of authors such as Le Shan, (1964); Idler, (1979); Scarry, (1985) and Morris, (1991). Skepticism from others such as



health professionals, who did not believe sufferers' symptoms or accept RSI as a genuine medical condition, exacerbated this. However, in the social context of sufferers' everyday lives, it was necessary for people to explain their ill health to others to elicit their help and support. For example, symptoms needed to be articulated to health professionals to enable them to diagnose the problem and to employers to gain entitlement to sick role benefits or to request the employer to make work place modifications. Family and friends too needed to understand what was happening to sufferers.

#### **9.12.4 Sufferers' explanations for RSI development**

To make sense of RSI, sufferers speculated about the possible causes of RSI development. Explanations for onset included: prolonged periods of writing, programming on a laptop computer, secretarial work involving almost exclusively audio typing, incorrect and overuse of the computer during undergraduate and postgraduate study, extended periods of mouse and keyboard use, poor posture, poor ergonomic set up of workstation and ignoring symptom onset. Given that computer users were dominant in this study group, these findings are perhaps not surprising. As seen in Chapter 3 on RSI, the literature indicated that computer users are a high risk group. Also implicated were working for long hours, insufficient rest and working in a stressful environment with worry about uncompleted work and tight deadlines. Stress (both physical and psychological) was often alluded to as an underlying contributory factor to RSI, such as physical stress from too much typing without sufficient rest and psychological stress from tight deadlines or conflict with an unsupportive manager. Sufferers noticed stress could exacerbate symptoms whilst body massages could ease tension and pain. The negative impact of stress on general well-being and muscle tension was recognised.

More unusual explanations proffered for RSI development were that RSI was hereditary, related to being a twin (cramped space as a foetus), increased susceptibility from having hyper mobility syndrome and having a whiplash injury which had left some residual structural weakness.

Despite the variable explanations cited above, the majority of sufferers in this study believed their RSI was predominantly a mechanical injury, caused or aggravated by work. This belief influenced the way RSI was experienced, sufferers' beliefs about RSI and pain and their expectations for its management.

## **9.13 Main theme 2: Seeking medical help**

### **9.13.1 Diffuse RSI as a medical and diagnostic challenge**

Sufferers' health care experiences highlighted the medical uncertainty surrounding achieving a diagnosis for non specific RSI whereby sufferers were sometimes conferred contradicting diagnoses by different health professionals. In one case, the same symptoms were diagnosed as tennis elbow by the GP but were attributed to trapped nerves in the neck by a chiropractor. Moving from a position of no diagnosis to having two conflicting diagnoses did not resolve the sufferer's diagnostic uncertainty, albeit the diagnostic possibilities may have been narrowed down. Littlejohn, (2007) an expert on RSI, highlighted the challenge clinicians faced in diagnosing diffuse RSI, stating RSI was easy to misdiagnose.

### **9.13.2 Diagnostic uncertainty**

The following excerpt provides insights into one sufferer's generalised view regarding the medical uncertainty about RSI in the ad hoc manner she felt sufferers were passed from one health professional to another within the health care system in efforts to discover what was medically wrong with them, and the impact this prolonged process had on sufferers' symptoms and employment prospects:

Participant P0027: 51 year old female with RSI for 3 yrs and 6 months

*"That is why we are passed around because, initially, most GPs think it is a bone problem so off you go to an Orthopaedic Consultant; who finds nothing but sends you off to Physio; who can't help and sends you back to your GP who then sends you off to a Rheumatologist; who may be able to help but if they can't it back to the GP; who then*

*sends you, if you're lucky, to a Pain Clinic or to a Neuro Surgeon for nerve conduction tests which are usually negative so it's back to your GP and so on. A right old merry-go-round as your pain is getting worse and unemployment looms."*

### **9.13.3 Sub theme: The multiple meanings and purposes of a diagnosis**

For many participants recovery from RSI was inconceivable without first establishing a clear diagnosis to identify and understand the medical problem as a basis for resolving it. Those who did not have a diagnosis held their recovery (and sometimes their life) in abeyance until they received one, viewing the lack of a diagnosis as an obstacle to their recovery and treatment. Having a diagnosis took on many meanings, could serve multiple purposes and was often perceived as protracted and difficult as illustrated in the quotes below:

Participant P002 36 year old female with RSI for 22 years (Group 1)

*"On one hand, a diagnosis helps enormously. It signals acknowledgement of problem. It tells you, and your employer, that it's not in your mind but is a medical condition. It's particularly important if your employer is not supportive to get a diagnosis. On the other hand, it can be difficult to get a diagnosis (tests often come back negative), and it may change every time you see a different doctor, which may lead to your boss thinking you are at it. It can also have a negative impact on your emotional state as it's very frustrating and stressful when you're in pain but nobody can tell you what it is."*

Participant P0033: 46 year old female with RSI for 3 years 11 months (Group 3)

*"A diagnosis is vital. How else can you treat and advise the patient if you don't even know what it is they are suffering with? I am certain that in my particular case, the doctors, occupational health and personnel staff that I was dealing with all suffered with such a degree of paranoia about the prospect of me actually having 'R-S-I' that this caused a huge obstruction and delay in my diagnosis, which eventually came about two and a half years after my first problems. If someone had the courage to make a diagnosis much sooner, rather than going for 'delaying tactics' then my condition may well have been reversible. The system seems to favour trying not to offend employers by suggesting that their staff may have been injured whilst in their employment, rather than prioritising the diagnosis of the injured employee".*

Participant P0031: 35 year old female with RSI for 6 years 9 months (Group 3)

*"It's much easier to deal with drs, employers, co-workers, friends etc if you can say I've been diagnosed with so and so. There is so much stigma around RSI (unless I'm imagining it) that to have a actual medical diagnosis of tendinitus or whatever helps. ...Although like someone else said the 1st thing people say is 'can't you get any compensation for that?'"*

Some of the meanings and uses given to a diagnosis are provided in Table 9.6:

**Table 9.6: Meanings, purposes and significance of a diagnosis**

**Being conferred a diagnosis had multiple meanings and purposes for this group:**

- A diagnosis helped to explain symptoms and establish what was medically wrong
- It eliminated some uncertainty by discounting serious/life threatening conditions
- It helped remove diagnostic uncertainty and enabled sufferers to move out of their liminal status in which they were considered neither sick nor well
- It conferred medical legitimacy and signaled acknowledgement of a genuine medical condition.
- A diagnosis made sufferers eligible for sick role benefits, without which, the "door slams in your face"
- It opened up treatment options and enabled treatment to be planned
- It helped counter accusations of malingering, feigning illness, being work shy
- It helped dispel notions of it being a psychological condition or the individual being a hypochondriac which carried greater stigma than physiological conditions
- A diagnosis was considered a pre requisite to recovery as it formed part of the process of understanding, accepting and accommodating RSI into their life
- It was easier to communicate with and to enlist help from others if they knew what their problem was e.g. when reconstructing their new self identity as an ill person
- A diagnosis could provide leverage for negotiating concessions at work, particularly if the employer was unsupportive
- It was vital medical evidence for the few pursuing legal action against an employer

- A diagnosis made a prognosis possible which could help reduce future uncertainty
- A diagnosis ensured RSI would be officially recorded in medical statistics to reveal the true extent of the problem, rather than being recorded as an undiagnosed case

According to Parsons (1951), medical professionals are delegated the responsibility for controlling illness on society's behalf including confirming or disconfirming illness by conferring or denying a medical diagnosis. When doctors were unable to provide RSI sufferers with a diagnosis, or if they did not acknowledge it or rejected its genuineness, this had serious repercussions for the individuals themselves which carried over to others with whom they interacted such as employers, family and other social contacts. For example, in the absence of a medical diagnosis, some workplace managers, colleagues and legal professionals doubted the authenticity of their condition. Moreover, if doctors were not able to provide a clinical name and substantiate sufferers' claims of illness, some employers felt this released them from any obligation to provide benefits such as workplace modifications.

#### **9.13.4 The meanings of negative diagnostic tests**

Negative diagnostic tests were greeted with disappointment rather than relief (compared to, for example a test for cancer or MS) as this was interpreted as meaning that their illness was not real. Despite being convinced that something was wrong with them, failed diagnostic tests were interpreted as refuting there was anything medically wrong with them or that the problem might be psychological or there was no medical problem.

Participant P0053 34 year old man with RSI for 2 years 11 months

*"I eventually persuaded my GP to refer me to a rheumatologists. I felt saved at this point because I was sure I must have something like this wrong with me. I was actually disappointed when the results came back negative as I so wanted somebody to tell me that I wasn't mad and that there was something wrong with me."*

Enormous relief was usually expressed when a diagnosis was conferred which helped reduce sufferers' anxiety and suffering. However the broad RSI label was also seen by a few to carry stigma because of the possibility of compensation, making it preferable to have a more specific clinical diagnosis.

### 9.13.5 Sufferers' encounters with health professionals

As mentioned in Chapter 3 on RSI, at least half of RSI cases involved non specific diffuse symptoms which were unaccompanied by discernable clinical signs and were consequently difficult to diagnose (Lynn, 2006). For such individuals, the difficulty in obtaining a diagnosis resulted in a protracted engagement involving multiple encounters with an array of health professionals. One diffuse RSI sufferer recounted having had over 60 hospital appointments over the past few years with specialists from Rheumatology, Pain Clinic, Pain Management programme, Occupational Therapy, and others. Whilst this number of hospital consultations seems high, this was not an isolated case, as many other sufferers too reported a succession of medical consultations. Moreover, sufferers were prepared to endure the discomfort and uncertainty involved in multiple diagnostic tests and examinations in order to achieve diagnostic resolution. Glenton, (2003) stated that ironically it was the lack of a diagnosis for patients with non specific back pain which prolonged their contact with medical professionals. Sufferers frequently felt health professionals did not believe their symptoms or believed they were 'all in the mind' or were told that RSI was not recognised as a medical condition. Health professionals were perceived as dismissive, did not understand their concerns or were simply baffled by their symptoms. Some health professionals informed sufferers they were unable to help them as they had been unable to find anything wrong with them based on negative diagnostic test results. Sufferers expressed their discontentment with health professionals in their negative comments about how little health professionals knew about RSI, referring to them as "allegedly knowledgeable medical experts", and describing some as useless, unsympathetic, ignorant and arrogant. Sufferers often felt that they knew more about RSI than most of the health professionals they saw and felt disillusioned by the very professionals they felt should be helping them, as illustrated in the following quote:

Participant P0052 49 year old female who had RSI for 5 years 9 months but now considers herself recovered (Group 5)

*"...it is sad that those whom we turn to for help often actually make things worse by trying to suggest we are malingering or sick in the*

*head! It would be better if they could just admit that they do not understand this condition and not blame the victim!"*

Suggestions of malingering or that RSI had psychological origins were considered to exacerbate their suffering. Sufferers felt doctors blamed patients when they were unable to find anything wrong with them, rather than acknowledging the medical uncertainty and incomplete knowledge of RSI. The negative medical encounters may reflect sufferers' frustration at being unable to find an acceptable explanation for their symptoms and doctors' frustration at RSI which challenged their medical competence and for which they could not offer much help, as discussed earlier in chapter 5.

Based on personal experiences and general observations, sufferers felt that the medical profession was highly revered in Western culture and the public was conditioned to respect, but not challenge medical authority and advice. However, the doctor's position as a highly knowledgeable expert was accompanied by high expectations of them to find solutions to patients' complaints and problems. Doctors failure to sympathise or believe sufferers symptoms as genuine, could have a negative impact on patient recovery. The following quote offers insights into how the medical professional was viewed:

Participant P0053: 34 year old male with RSI for 2 yrs 11 months (Group 5)

*"The society that we live in does, and has done for some time, teach us to place an immense level of trust in doctors. We are not encouraged to question them in any shape or form let alone doubt what they are telling us. Thus we grow up feeling they are somewhat infallible. Unfortunately some doctors also seem to grow up feeling they are somewhat infallible. This then places an enormous responsibility on them. We go to see them and expect (unfairly in some cases) to be told what is wrong with us and what we can do to make it better. If we then hear from them, or they even give us the impression, that they do not sympathise with pain we are feeling or worse still do not believe us, this can have a devastating effect on patients and really set them back."*

Sufferers felt that when doctors experienced difficulty in diagnosing RSI, instead of blaming the patient, they should be more realistic about what help they could offer them, offer some empathy and be willing to explore all options. In the following quote the sufferer provides insights into what she felt doctors should say:

Participant P0052, 49 year old female (Group 5)

*"They need to be able to say "I appreciate what you must be going through, however I am not exactly sure what the problem is, we will need to look into this further". How much better must this be than saying "rest it and comeback in six months" or "are you sure it is sore" or "there does not appear to be anything wrong with you" or even worse "there is nothing wrong with you". There is no failure in admitting you do not have all the answers. Then resources can be put into trying to find other professionals and/or who may have experience in these areas.*

There was anger at the way some 'medics' responded to sufferers and sufferers felt that doctors should assume patients symptoms are genuine and investigate them as best they could. Doctors should take RSI seriously from the outset, given the potentially serious consequences for individuals and their families. Although doctors should be honest about the limits of medical knowledge about RSI and its management, they should be positive about what they could offer.

#### *9.13.5.1 Searching for 'good' doctors and their characteristics*

RSI sufferers generally believed that many health professionals had a negative attitude towards RSI and were unknowledgeable about RSI. As a result, some sufferers sought recommendations for 'good doctors' from other sufferers to increase the likelihood of obtaining a positive medical outcome. 'Good doctors' were characterised as those who were sympathetic, knowledgeable about RSI, were experienced in treating RSI, listened to sufferers and understood their concerns, took them seriously and were honest about their own and medicine's limits. In addition they offered concrete solutions, such as providing a diagnosis, arranging for diagnostic tests and providing treatment to help manage the condition. Sufferers attached high importance to the human qualities of listening, understanding and believing sufferers and not being dismissive.

#### **9.13.6 Sufferers' acquisition of medical knowledge and expertise**

Through sufferers numerous contacts with health professionals combined with information acquired from other sources, such as the RSI support group network, the internet and other media and family and friends, sufferers gradually accumulated



a wealth of knowledge about RSI and acquired practical expertise in its management and treatment. Sufferers often progressed from having little or no knowledge of RSI to considering themselves more knowledgeable than the health professionals who treated them. The importance of 'lay expertise' has been recognised and used for clinical benefit in the NHS Expert Patient Programme in which people with personal experience of pain help educate other pain sufferers and medical professionals.

#### **9.13.7 Efforts to relieve RSI pain**

RSI sufferers drew on both traditional medical interventions and complementary therapies in their pursuit for pain relief. Typical professionals consulted were the GP, pain specialists (usually rheumatologists and orthopaedic surgeons), physiotherapists, osteopaths or chiropractors. Interventions routinely used by sufferers included: pharmacological interventions, remedial massage, acupuncture, traction, tens machine, and surgical procedures. Also used were ice packs or warm baths, support bandages and splints. A few sufferers were offered multidisciplinary treatment at pain clinics, usually after all other treatment options had been exhausted. Sufferers described pain relief as short-term with the pain never completely disappearing. Some sufferers were advised by health professionals to give up computer work, but this solution was untenable for many who depended on computers for their livelihood and described this situation as "a catch 22."

Although obtaining a diagnosis was paramount for this group of sufferers, having a diagnosis did not guarantee its successful management. Even those sufferers given a clinically accepted RSI diagnosis, could still experience difficulty in obtaining pain relief. One sufferer with De Quervain's disease recounted her ongoing struggle for pain relief, where despite four operations (two on each wrist), physiotherapy, occupational therapy and cortisone injections, she remained in pain and off work sick a year after her last operation. This contradicted the ideal notion held by some sufferers that obtaining a diagnosis would be the much-awaited solution to their pain as a diagnosis was expected to be followed by effective treatment.

### 9.13.8 Apportioning responsibility for RSI management

Views about who was responsible for managing RSI were divided between sufferers who considered managing illness to be primarily the doctor's 'duty', (since this was considered to be what doctors were trained and employed to do). In contrast, others believed responsibility for managing RSI lay largely with the individual, whilst the notion that it was a joint responsibility between the patient and the health professional was also suggested. Views about the responsibility for managing RSI were not static and could change over time as illustrated in the following excerpt:

Participant P0031: female with RSI for 6yrs 9m (Group 3)

*"I think you do have to learn to manage your own condition. When it first starts all you want is for someone to wave a magic wand and make it better – it takes a long time to accept that no-one can - it's up to you. Although perhaps psychologically you have to go thru the first bit in order to get to the adaptation and acceptance bit (bit too deep for me)."*

### 9.13.9 Threat of RSI compensation compromises health care

Sufferers' experiences in this study were still considered to be influenced by publicity surrounding the rise in RSI compensation claims in the 1980s (Willis, 1986; Reid et al, 1991; Ewan et al, 1991). Sufferers believed this fear of compensation claims was a primary reason why some doctors delayed or obstructed the sufferer's path to a diagnosis. As seen earlier in Chapter 3, the potential for RSI to be compensated in still being tested in the UK courts and remains a confusing area. Sufferers felt that doctors were faced with a conflict of interest in which they could either side with sufferers or alternatively with their employers, by conferring or denying them an RSI diagnosis. Sufferers felt that doctors' main priority should be to support them as patients. In denying sufferers an RSI diagnosis, doctors were perceived to be protecting employers' interests.

Participant P0055: Group 5 female age unknown

*"I cannot understand why considerations of compensation by third parties influence doctors' willingness to care for their patients. Doctors should be there to support their patients. Early diagnosis*

*and appropriate treatment would be a major contribution to this and could eliminate compensation claims.”*

GPs were described as ‘sitting on the fence’ rather than conferring a firm diagnosis. One person said her GP had changed the RSI diagnosis initially entered on her sick line to cervical spondylosis, once she increasingly was off work sick.

As discussed in Chapter 3, there has been considerable opposition to the use of the term ‘RSI’ because it implied the existence of some injury and apportioned blame to employers (Hall and Morrow, 1988; Littlejohn, 2007). The medical encounter in this study therefore seemed to sometimes consist of three parties - the doctor, the RSI sufferer and the invisible but palpable influence of the legal aspects of RSI. Sufferers in this study felt the doctor’s position was not neutral; rather he or she had to protect either the interests of sufferers or employers.

#### **9.13.10 Becoming more assertive in help seeking (taking greater control)**

Some sufferers took more responsibility for their own health care by becoming more assertive with health professionals and were even prepared to make a nuisance of themselves in order to exercise their right to good/alternative treatment. However, sufferers conceded that ‘fighting for their rights’ was physically and mentally exhausting and would be difficult to achieve without the support of family and friends. A sufferer from New Zealand commented on the lack of knowledge of health professionals in managing RSI and the variable quality of treatment. These sentiments were mirrored in many other e-mails.

Sufferers felt it would be highly beneficial to patients if alternative and orthodox medicine were integrated. It was felt that Western medicine could learn from the many alternative therapies which took a more holistic approach to understanding the human body and mind, such as cranial osteopathy, acupuncture, Reiki, and others which had helped RSI sufferers.

## **9.14 Theme 3: Interference with social roles and activities**

The functional limitations imposed on RSI sufferers affected sufferers ability 'to do' things and 'to be' e.g. be a parent, spouse, family member. As noted in the introduction, RSI had the potential to interfere with all aspects of sufferers' lives creating difficulty in undertaking paid work, parenting, housework (e.g. cooking, cleaning, ironing, doing the dishes and shopping), and self care activities such as washing, dressing and eating. In addition it could interfere with people's leisure, educational and social activities. Whilst some activities/roles could no longer be carried out because of RSI, others had to be curtailed, or could be continued but in a different way to before. Interference could vary from being a relatively minor disruption which could be accommodated, to more far-reaching limitations such as job loss. Sufferers found it difficult to do many things involving lifting, carrying, pushing, holding – manipulating hands to turn a key, cutting up food, undoing buttons and opening zips, stirring a pot of tea or shutting windows. Conversely, when sufferers did improve and regain their health, their improvement was measured by the things they were now able to do such as being able to wash their hair, use zips, drive or sleep.

### **9.14.1 Being a parent**

Having RSI impacted in many ways on sufferers' role as parents. For example, one sufferer who had changed from secretarial duties to child minding because of RSI, realised she was experiencing difficulty in her role as a child minder which gave her reservations about whether she could take care of another child of her own, which was something she really wanted. Another young mother recalled an instance of finding herself in a desperate situation where she was unable to look after her baby and had to call her mother for help:

Participant P0049:34 year old female with RSI for 1 year 11 months (Group 5)

*"I had to call my mother in emergency as my baby was lying on the bed, nappy off as I was unable to put a nappy on or indeed hold her*

*as I was in so much pain. I went to A&E and was seen by a male doctor who said I needed to be referred to a hand surgeon."*

A father expressed huge disappointment at being unable to hold his newborn baby saying he could barely hold her let alone change or feed her and felt guilty about being unable to help his wife with childcare.

#### **9.14.2 Maintaining a household**

Maintaining the flow of routine daily activities such as housework was another important aspect of life which had to be reorganised in response to RSI. Some took a pragmatic approach to housework in which it was prioritised into "essential" tasks which had to be done, and others which were less important "extra" things, such as tidying up and cleaning the house, which could be postponed. In the following quote, this sufferer allocated a maximum of one hour a day to dealing with non essential housework with the remainder of time being reserved for the most important tasks.

Participant P0056: 40 year old female with RSI for 3 years 8 months (Group5)

*"I take some of my ironing to be done, otherwise I do it on a needs must basis. The house is invariably needing cleaned or tidied as I cannot use my arm for more than an hour a day on "extra's", I can barely cope with the essentials."*

Functional limitations due to weakness in the arms and wrists were seen in daily activities such as cooking which became problematic because of difficulty experienced in lifting heavy saucepans and cutting up food. This was also accompanied by the embarrassment at needing to ask others for help such as being unable to unzip or unbutton trousers to go to the toilet. Due to impaired motor functioning, sufferers said they kept dropping and breaking things. Some resorted to drinking out of light weight plastic cups or a baby's cup as these were lighter and unbreakable.

Participant P008: 45 year old female with RSI for 25 years (Group 1)

*"I was rinsing off some spaghetti the other night and my fingers in the affected hand just let go of the colander - and the spaghetti landed in*

*the sink. That was the end of another meal! I can't cut up my food properly or clean my teeth very well (although I have now bought a sonic wave toothbrush which helps with this task). When the pain and motor function is really bad, it's embarrassing to have to ask someone to unzip/unbutton my jeans or trousers so I can go to the loo, or having to ask my husband to cut up my food for me because I can't manage to do this simple task myself."*

RSI had the potential to render individuals unable to perform even 'simple tasks', with the implication that one should be able to independently do basic things such as brushing teeth, cooking, or going to the toilet. Also highlighted are the feelings that this inability to do things evokes, such as embarrassment. The marital relationship has also changed since the sufferer's husband is assuming some duties as a caregiver such as cutting up food for her to eat. There is a sense of frustration at being unable to meet her own expectations of carrying out what she describes as 'simple tasks'

### **9.14.3 Interference with shopping**

Whilst some sufferers became resourceful at finding alternative ways of doing things, others found that things easily done in the past now had the potential to cause frustration because it took them longer to do than before and more importantly, took longer than others expected them to take. One sufferer described a scenario in the supermarket in which she experienced difficulty opening her bag and purse to pay for her shopping. Because this took longer than 'normal', it caused her frustration and embarrassment as she felt she was keeping the shop assistant and other shoppers in the queue waiting while they watched her, as illustrated in the excerpt below:

Participant P003 28 year old female with RSI for 2 yrs 1 month (Group 1)

*"After having a fairly good day, I went into our local supermarket tried to open my purse and hey presto my right wrist went again. It was so frustrating while trying to cope with being unable to open your bag, or purse and trying to grip a coin especially when you have a bored shop assistant who just looks at you and the queue of people waiting."*

This excerpt highlights the underlying pressure not only to perform tasks but also to perform them at a speed acceptable to others and considered as 'normal' speed. Sufferers' inability to do valued activities as they did previously had a significant negative impact on their sense of self and identity. As some sufferers were unable to drive a car, this meant they had to either rely on others to take them places or forego car trips and find other ways to travel.

#### **9.14.4 Interference with social and leisure activities**

Leisure activities were also affected by RSI such as being unable to play the piano, create mosaics, cycling, yoga, kayaking, exercising, going to the gym and holidays. Some of these restrictions in activities had a devastating effect on some individuals. Sufferers were often reluctant to participate in social activities due to the potential embarrassment of for example being unable to sit for any length of time (e.g. cinema), fear of dropping things, not being able to cut up food (restaurant) or boring others with incessant talk about pain. Whilst the decision to withdraw from some social activities was made consciously through declining social invitations, social contact was enforced for others through being unable to drive to visit family and friends or from having to ask someone else to drive them. However sufferers acknowledged that other people too eventually stopped contacting them. Holidays were problematic from not being able to keep up with other family members but at the same time not wanting to spoil the family holiday. Special occasions such as birthdays became less special and became an occasion to be given devices, books, exercise tapes or drug vouchers to help them with RSI. One participant said she missed the 'daft presents' like homer simpson socks she used to get, instead of RSI-related aids. Her birthday became yet another reminder of RSI.

#### **9.14.5 Interference with sleep**

Sleep disruption affected many RSI sufferers and could result from being woken up in pain, from rolling over onto a painful wrist, from being unable to get comfortable, to having nightmares, possibly as a side effect of RSI medication. Side effects of medication taken to aid sleep included making them feel 'spaced out' or like they

had a hangover in the mornings, creating difficulty in getting up in the morning. Therefore these positive aspects of medication (enabling sleep and rest) and negative side effects (unable to get up in the morning) had to be balanced out, since taking stronger doses of drugs to help sleep at night could make the effort of getting up in the morning too great. A further consequence of sleep deprivation was that they woke up feeling tired rather than refreshed which then made the days even harder to deal with. Some wore splints at night whilst others said they experienced difficulty sleeping even with 50mgs Amytriptiline and 2 dihydrocodiene and paracetamol tablets.

#### **9.14.6 RSI interference with paid work**

Work was one of the key areas of sufferers' lives which RSI impacted on the most. Changes were often made to avoid or minimise pain and discomfort at work usually through negotiation with the employer. This could involve spending less time directly working at a computer, working fewer hours, undertaking other non-typing duties, changing to a different job or completely changing career. Some sufferers lost their job when they were unable to continue working. Others found ways to continue working, for example by learning to use new technology, such as voice recognition software which allowed them to dictate rather than type. This technology changeover had enabled several people to retain jobs they might have otherwise lost. Other computer-related changes included trying a variety of different pointing devices to avoid mouse use. However, in addition to the many physical changes made at work, mental changes were also made, such as a changed attitude towards work, whereby sufferers prioritised their own health above work demands. A few who returned to work following sickness absence were disheartened to find RSI had returned which neither they nor their employer had expected. Being off sick was a difficult time for sufferers since whilst they had time on their hands, they were unable to do all the things they would normally have enjoyed doing in their spare time when working. One person said that when he had been off sick and had had too much free time, he ruminated too much about the negative aspects of RSI which could have spiraled into depression. Sufferers also felt that there were implicit cultural expectations that if a person was off work sick, they were obliged to stay at home. Some questioned why they shouldn't go for walks whilst off sick from work, since the



problem was with their hands and arms, not their legs and it was good to exercise and engage with the outside world.

Sufferers workplace experiences were at times exacerbated by the legal implications of RSI as an occupational injury which sufferers felt hindered their efforts to seek medical legitimization (see theme 2). Employers were seen as looking for a 'quick fix' to the RSI problem such as changing equipment, rather than tackling fundamental underlying issues. As mentioned in chapter 4, Burton et al, (2008) have suggested that the term 'work-related' in RSI be replaced with 'work-relevant' to avoid the causal link between RSI and work in efforts to move away from legal implications of work place injury.

#### *9.14.6.1 Importance of work in health*

A major undesirable aspect of pain for RSI sufferers was its unrelenting nature, in many cases lasting years. One participant described being off work sick for eight months with RSI and being devastated when within two weeks of a phased return to work, he was off sick again. He found it inconceivable that such an extended rest period had not eliminated his RSI problem. He surmised after speaking to others, what whilst rest could control the pain, it did not necessarily aid recovery. The pain management literature now contraindicates extended rest periods because of the detrimental effect on physical deconditioning (Waddell and Burton, 2005; Burton et al, 2008) and because it removes the structure and meaning which work gives to many people's lives (Good et al, 1992; Blustein, 2008). Work is considered vital for the development, expression, and maintenance of psychological health (Waddell and Burton, 2006; Blustein, 2008; Burton et al, 2008). Work was a central aspect of life and earning one's livelihood represented an important means for people to interact with their social, economic and political environment (Blustein, 2008). Work is also an important part of a person's identity.

## **9.15 Theme 4: Managing/coping with changes imposed by RSI**

A variety of strategies were developed to cope with and manage the changes which accompanied RSI, mostly discovered through a process of trial and error. Medical interventions to manage pain were sought and used by most sufferers in this group initially, even if they subsequently opted for alternative therapy. A principal strategy was to avoid whatever sufferers perceived to be the cause of their pain, such as computer use. Another strategy was to discuss their concerns with fellow sufferers in the supportive environment of an e-mail discussion list for RSI sufferers. Other strategies adopted included letting the body set the boundaries of what could and could not be achieved, termed 'listening to the body'. Activities were stopped, replaced or their pace, frequency or the manner in which they were undertaken altered. For some, coping meant lowering their own expectations about e.g. acceptable standards of housework, or re prioritising goals such as letting less important things slip, or being less house proud and fastidious about cleaning the house, ironing and tidying up. It meant doing things like shopping in a different way, such as shopping online to avoid physical carrying/lifting, since groceries could be delivered right up to the door.

Gadgets and implements were used to ease routine activities in the home such as an electric can opener, electric mixer/slicer, upright cylinder vacuum and a jar opener. Collectively all these small changes made a big difference to their overall ability to cope. Learning to ask for help with tasks such as loading heavy shopping into the car at the supermarket was another strategy. Other changes included buying sliced bread instead of whole loaves to avoid having to cut it, finding compromises such as roughly chopping vegetables instead of trying to neatly slice them, asking for help in removing lids of jam jars, driving using one hand and resorting to sleeping alone in the spare room to enable arms to be propped up at night.

A further important aspect of coping was learning about RSI and its management through information amassed from different sources such as directly from health professionals, self help books, medical journals, the media, the internet, and through 'lay expertise' such as family and friends. Over time, sufferers accumulated a vast amount of knowledge and developed practical expertise in managing RSI. This

knowledge base often increased from that of a novice to becoming an 'expert'. Sufferers learned from their own personal experiences and compared these to the experiences of others. Davison et al, (2000) have referred to online support groups as 'venues of social comparison'. The knowledge and expertise acquired by sufferers was considered by them to be 'hard won' since it was very difficult to find elsewhere.

There was considerable variation in the way individuals coped with having RSI. Some individuals had found coping very difficult and even retrospectively were unable to explain how they had coped at the time, but only knew that they had. However, coping often involved extra responsibility being assumed by other family members – often the husband but occasionally the wife or partner. One participant said she coped simply because she had no choice as she had the responsibility of taking care of a baby, and on reflection, felt she had probably endured more hardship because of the baby than she would accept now.

Participant P0049: 34 year old female with RSI for 1 year 11 months (Group 5)

*"I don't actually know how I coped - I just did. My husband had to do many extra chores - I couldn't chop vegetables, I would drop things and break many jars/plates/glasses in the kitchen, turning keys in locks was impossible with my right hand - as was general things like doing up bra straps, washing and drying hair. I think I coped because I had to look after this baby and therefore put up with a lot more than I would now."*

Managing RSI was time consuming and demanded considerable time and effort which sufferers would have rather spent doing more pleasurable activities. One sufferer explained that she sought to achieve a balance between the attention demanded by her body and other aspects of her life. Despite feeling despondent about having to continually exercise to manage RSI, it was also felt that if this strict exercise regime was not adhered to, sufferers would pay the price later. RSI therefore required ongoing effort which could not be dispensed with; otherwise they would experience greater pain later. One person's exercise routine consisted of three gym sessions a week, twenty minutes of stretching every night, taking regular micro breaks and frequent stretches at work. RSI was constantly kept in mind by some sufferers to avoid the risk of 'overdoing it'. One person who was aware that

being hyper-aware of pain was considered undesirable felt equally pain could not be ignored, since pain was present for a purpose and one was obliged to listen to the body.

In common with Reid et al's (1991) study, a few sufferers identified specific turning points in coping with RSI. For example one sufferer said his turning point was the culmination of two distinct events: finding a physiotherapist experienced in dealing with RSI sufferers who understood his plight and started him up on pacing exercises and secondly, taking up the suggestion to try the Alexander Technique. The Alexander Technique was considered a complete revelation which transformed his life. However, although he considered himself much improved, his assessment of his current state of health was conveyed in terms of everyday things he could or could not do:

Participant P0053: 34 year old male with RSI for 2 years 11 months (Group 5)

*"I still can't write, Cook, push a pram, kayak or a thousand other things but I work full-time (with the help of an understanding employer and voice-activated software-which I am using at the moment). I can also at least play (to some extent) with my children, feed them, and offer some help with childcare. I still have off days, frequently suffer pain but have improved so much."*

This sufferer's comments suggest that despite RSI pain, he had been able to move forward with his life, albeit he was less active than previously. Having an understanding employer and the use of voice recognition software technology had helped him to remain in work. Moreover, he was still able to be actively involved in looking after their children with his wife.

A female in the group identified her turning point as being the confirmation by a rheumatologist that her RSI was work related (which was an enormous relief to her), after which he referred her to an occupational therapist who gave her a book on alternative therapy which persuaded her that the only way to recover from RSI was by taking the alternative medicine route. Positive thinking, meditation, going for walks, exercise and taking various vitamins and minerals such as Glucosamine, Cod Liver Oil, Garlic supplement, Cider Vinegar, Vitamin B12 and Calcium with Vitamin D, were amongst the strategies she used. She felt there were days when she felt

she couldn't go on, which required tremendous willpower to convince herself that tomorrow things would be better. She concluded that the only way to live with RSI was to accept that the individual could not return to the life they had before, but just work with what they had.

Managing RSI was made more difficult for some by the conflicting advice given to them by health professionals such as information regarding the right balance between resting arms to aid recovery and work. One individual said that over the years she had been advised not to exercise, then to exercise and had been told that she had been doing the wrong thing at any one time. However, she had found doing gentle exercise and stretching more beneficial than not doing anything at all. She said she stopped exercising because of RSI and now had no strength in her arms. This suggested there was considerable confusion in defining acceptable pain limits to work through safely and when activities should be stopped.

Some said that coping was difficult because life became an obsession with RSI and avoiding/ treating pain. Sufferers felt that others who had never experienced chronic pain could not understand what it was like for them. They found it hard to explain their pain to others and had to resort to using metaphors such as its like having toothache in your arms, because toothache is something most people have experienced. Sontag, (1989) stated that metaphors were often used in illness. Others who had to stop doing certain things because of RSI were very angry that they had developed RSI and were frustrated because they were unable to do the things they wanted, which could be something as simple as opening a bottle.

When things got too much, some sufferers coped by "going into hiding for a short while" or 'crept under the duvet'. Some took it upon themselves to warn and help other sufferers, but became frustrated if their attempts to warn colleagues of the potential dangers of RSI and computers were rejected. However several who had at least partially recovered from RSI were involved in running support groups.

Developing RSI was viewed by a few people as an indirect message to review and change their life situation with an opportunity to do something different with their lives.

### **9.15.1 Coping with uncertainty**

A major consequence of the many changes brought on by RSI was the uncertainty it created in sufferers lives about their illness, recovery and their future. Whilst many sufferers became preoccupied with managing and coping with RSI on a daily basis which demanded their constant attention and consumed much of their time and effort, the future also had to be considered. Some sufferers said they found the future too daunting to contemplate as it looked bleak, and were very uncertain about when and even if, they would recover from RSI. Many sufferers still looked to the past and their former way of life and the activities they engaged in prior to getting RSI, with some wanting to return to that time and place in their life. The future was considered to be so scary to think about, that some said they were almost in denial about their long term future. This made it difficult to plan their lives and set future goals. This may be important for considering its clinical management as this uncertainty needs to be managed to enable individuals to move forward with their lives rather than to look back to the past.

## **9.16 Theme 5: Issues related to legitimacy**

Although pain was a main symptom of RSI, the nature of pain was such that their pain experience was a private experience which could not be physically 'seen' or accessed by others, rendering it invisible to others. Moreover, RSI was also 'invisible' to medical professionals who checked the body for signs of disease through diagnostic testing and examinations. Because of the hidden nature of RSI, sufferers occupied a liminal space which meant they were considered neither well nor certified sick which hindered access to sick role benefits. Many negative consequences followed on from not having a diagnosis. A primary consequence was that they were unable to obtain medical validation and acknowledgement of their suffering. This had further implications since in the absence of medical legitimacy, others questioned its existence which could result in their suffering being delegitimised. The ambiguous medical and social status of RSI as an illness, disease, occupational injury or condition was confusing for sufferers and many health professionals alike, and was an important factor affecting sufferers' experience of illness. Some of the confusion surrounding the medical status,

invisibility and consequences of RSI for the individual is exemplified in this sufferer's comments:

Participant P003: 28 year old female with RSI for 2 years 1 month (Group 1)

*"I've had problems for over 2 years now with this disease. Well I say 'disease', but you can't catch it, you can't be infected with it and you certainly can't see it, but believe me I can feel it. This debilitating injury now controls the majority of my life, work and personal. Its not like a look 'injured', I have 2 arms, 2 legs and 10 fingers and toes, I can walk, talk, hear and see, I don't wear a brace or a cast or have a disabled badge, yet I have a disability that is forgotten about by others because its not visible to the eye!!"*

This quote highlights several important issues which were common in RSI. Firstly its hidden nature meant it was invisible to others, so unless the sufferer told someone they had RSI, others would be unlikely to guess this. The ambiguous medical status of RSI is also evident with questions regarding its disease status and recognition that RSI did not conform to what one would traditionally define as disease nor to what most people would associate with disability. However she emphasised her own certainty about the subjective symptoms felt and highlighted the hidden nature of RSI disability since outwardly she appeared 'normal and healthy' rather than injured, diseased or disabled. This sufferer talks about RSI as an injury, consistent with the majority view in this study. However her main point is that she suffers with a disability which is not evident to others which resulted in delegitimation. The quote also highlights how being ill or sick carried expectations of being able to demonstrate this to others, be it health professionals or others and the expectation to look a certain way in order to be considered ill. Her outer normal appearance belied her inner subjective feelings which did not count unless they were medically confirmed.

A related issue was that since RSI was largely invisible to others, it elicited less sympathy and understanding. One sufferer said that it took a month off work and the presence of visible surgical scars to convince her employer that her RSI was a genuine medical problem. She considered the visible medical evidence of a surgical scar to be powerful factor in eliciting a change in her employer's attitude.

Participant P002: 36 year old female with RSI for 22 years (Group1)

*“... He [her employer] made me work back the hours I lost for physiotherapy sessions, which didn't exactly help my recovery, but after the operation and a month off work his attitude changed for the better. I suppose the fact that I had to have an operation and came back with a huge big scar on my arm made him realise that I really did have a problem. “*

The absence of any externally visible signs of pain and disability led several individuals to use medical symbols such as support bandages and wrist splints not only to ease their pain, but also as visual cues to draw the attention of others to their invisible disability as well as to remind themselves not to ‘overdo’ things. Sufferers said they wore a wrist splint on occasions to "signpost" their injury, so that people would know that “something is wrong.” Only one person said he wore them solely because they helped the pain and not to signal his problem. Another person commented on the changed attitude of others towards her when she wore her wrist splint and received many offers of help eliciting a more sympathetic response.

#### **9.16.1 Feeling judged by others**

The invisibility of RSI made some feel that their actions were being judged by others when they were unable to perform as others expected them to. This occurred in different settings from feeling others judged them to be lazy because they could not exercise vigorously like others at the gym, to taking too long to open shopping bags or purse to pay for shopping at a supermarket. Others felt doubted about the genuineness of their illness when they were on sick leave, especially since there were no outward visible signs of disability or pain. The excerpt below illustrates this feeling of being judged by others and the desire for some proof of it to convince others.

Participant P0051: 47 year old female with RSI for 3 years (Group 5)

*“Sadly it is all too familiar a story. I met a friend on the bus today who I hadn't seen for a long time. After asking me what I was now doing, she was amazed when I told her I was on long term sick leave. "But you look so well." I thought how many times have we all heard*



*that one? I just wish there was a test available to prove RSI does exist.”*

Being doubted could extend to close family such as the marital partner and siblings when doctors could find nothing wrong. RSI invisibility meant sufferers received overt accusations of malingering as well as tacit remarks about RSI which made the pursuit of a diagnosis all the more necessary as this could legitimise their pain and ‘prove’ their suffering to others. One sufferer who had successfully claimed compensation from her employer said she had been called a liar by them and said she used to cry because no one believed her. She expressed enormous relief at eventually being believed through a successful court case. The medical invisibility of pain and the way health professionals interpret and convey this to sufferers has important clinical implications for RSI management. The manner in which health professionals relate to patients and convey information to them has a significant impact on how sufferers feel and ultimately their recovery.

#### **9.16.2 Lack of social awareness and understanding of RSI**

Sufferers’ routine accounts of being disbelieved made them wish that there was greater social awareness of RSI in the same way as people knew about cancer and its different forms. Whilst RSI sufferers recognised that public fundraising efforts would not be directed at RSI research in the same way as for cancer, they nonetheless felt RSI needed to be better understood by the many stakeholders in society as this might help clarify the misunderstandings about RSI.

Participant P0010: 31 year old male with RSI for 2 years (Group 1) British national living/working in US

*“I dont expect RSI’s to ever get a profile in the public’s perception like cancer, but if it had a higher profile this would make it more understandable to employers, friends, family, random people who look at you funny when you can’t do something, unions, politicians, funders of heathcare research etc.”*

It was felt that whilst RSI was not perceived as fatal, there was still an urgent need to inform health professionals about the severity of RSI pain despite its invisibility, and get them to treat sufferers with care, sympathy and urgency.

### **9.17 Theme 6: Changes in financial circumstances**

RSI often had an adverse effect on family financial circumstances through affecting sufferers' ability to engage in paid work resulting in loss of earnings through job loss or a reduced income from working reduced hours. The consequences of reduced income could result in having to down size their home, having to draw on funds saved for retirement, worry about how they would be able to financially support their children's university education, having fewer holidays and loss of financial independence by becoming financially dependent on their partner.

In addition, RSI affected personal and family finances in other ways such as money spent on medical prescriptions, seeing healers such as osteopaths who were not available within the NHS system, having massages, purchasing voice recognition software (for home), on Alexander Technique lessons etc. One sufferer estimated some of the financial outlays on RSI as follows:

Participant P0031:35 year old female with RSI for 6 years 9 months (Group 3)

*"I've ...spent money on prescriptions, osteos, ice/ heat packs, massagers, VR software, microphones, acupuncture, Alexander technique lessons etc so we must be talking £3000 plus. I had to work part time for a few months in 2001 because I was ill so I lost around £2,400 in income that year. I've just spent extra money on an automatic car so it's less pressure on my hands so that's another extra cost. I've been lucky tho and kept working so I've been able to afford these things. I can't see that someone on sick/ disability could."*

Another sufferer said her being unable to work and contribute to the family finances meant they were now frequently overdrawn. Many worried about their financial situation and reviewed their options for generating income despite RSI. One sufferer said he worried about his financial survival in the future as the family breadwinner.

## **9.18 Theme 7: Importance of support in RSI**

RSI sufferers needed support from several sources to help them cope with the considerable changes which RSI introduced into their lives. How effectively they adapted to these major life changes in their roles, routines and identity was important in shaping RSI sufferers' experiences. RSI sufferers' illness occurred in a wider social context in which it was influenced by the workplace, the health care service, government benefits agencies, family and friends as well as the individual's inherent resources to cope. The support received from these different areas of sufferers' lives was variable, but collectively shaped sufferers' experiences.

### **9.18.1 Workplace support**

RSI management in the workplace was a significant factor in influencing sufferers' experiences. The findings from this study suggested sufferers rarely found their employers to be supportive with very few commending the way their RSI had been managed at work. Negative comments were often expressed about employers who were generally considered to be unsupportive, did not understand their predicament, did not want to spend money to help them or wanted to downplay the possibility of RSI. Work colleagues were also perceived as unsupportive. This is consistent with the findings of Dorland and Hattie's (1992) Australian study in which RSI sufferers described their work colleagues as "psychologically disruptive". Furthermore employer support was needed when sufferers were off on sick leave, particularly if this was long term as being away from work for long periods alienated sufferers from work colleagues and the work environment. Moreover, long periods away from work did not appear to resolve the RSI problem as sufferers reported flare ups soon after returning to work. However, one sufferer who had been off sick for a year, said she considered keeping in touch with her manager at work as a way of coping. The importance of employers maintaining contact with sufferers during sickness absence is highlighted in the report by Burton et al, (2008) on the management for RSI.

### **9.18.2 Support from health care professionals**

Support from health professionals has already been covered in the medical help seeking theme. It is included here because it is an important component of the overall support people needed. Whilst sufferers sought support from health professionals, they perceived the level of this to be highly variable. Support was needed from health professionals in the form of acknowledgement of their suffering, to be believed and given effective pain relief. Sufferers had high expectations of health professionals based on their professional training, experience and position as medical experts in society. Disillusionment followed when health professionals did not meet these expectations. The time delay involved in getting the appropriate support was also an important factor. One sufferer highlighted how a delay of a few months waiting to see specialist had meant that her condition had deteriorated so much during that period that surgery was the only solution.

### **9.18.3 Support in the home**

Having RSI involved many family changes in roles and responsibilities in efforts to accommodate the person with RSI. Sufferers needed practical, emotional and financial support during illness to help manage everyday life and activities such as dressing, shopping, cooking and housework. Daily routines were organised to accommodate sufferers' needs and limitations by delegating extra duties to others who took on the role of caregivers. This was difficult in some cases when the sufferer was themselves the primary caregiver for someone else, such as the case of at least two women in the study who were carers for their husbands. Even in cases where the RSI sufferer was able to continue working, they still needed concessions at home since all their energy was used to keep working full time and they were unable to cope with anything more. One individual described how her partner became her main carer, preparing meals, doing the housework and shopping, despite having a 100 mile commute each day.

Sufferers whose partners and families were supportive were very grateful for the support and understanding they received from them. It was important for sufferers to be believed by family and friends and to understand what they were going through and the difficulties they faced. One man praised his wife for her whole-hearted support and empathy regarding his problem which others could not physically see. He said that whilst she couldn't cure his problem, her understanding really helped him.

#### **9.18.4 High value of peer support**

The opinions of other RSI sufferers in the online support group were held in high regard and valued on the grounds that they had personal experience. Individuals sometimes acted on the advice of others, believing them to be more knowledgeable about RSI than some health professionals. Also the more assertive members in the support group encouraged less assertive ones to push harder to get the help they needed on the basis that everyone had a right to proper treatment. The support group setting was viewed as a valuable source of information unobtainable elsewhere, and a place to exchange and share experiences and information. Obtaining the support of others was considered highly important in coping with RSI.

#### **9.18.5 Consequences of no support**

Some sufferers who said they had received little support from either their workplace or medical staff said they felt isolated. In one case self doubt, general skepticism about RSI and lack of support had led to a lack of confidence in telling others about their RSI problem and resulted in the individual trying to cope with RSI alone without any direct support. Social support has been reported to be an important moderator in a person's response to illness (Sarason et al, 1985).

Participant P0052: 49 year old female with RSI for 5 yrs 9 months but now recovered (Group 5)

*"Now I know supporting people into a self help approach is critical. If I had not had the help of a good physio I would have spiralled down*

*into over protectiveness. People do need help with the progress of their recovery or they can stuck. You have to learn to manage the pain and to balance rest and exercise and the paramenters of these change over time.”*

### **9.19 Theme 8: Changes in self and identity**

The majority of changes associated with RSI were adverse physical changes which had a profoundly negative impact on sufferers' sense of self and identify. Having RSI forced sufferers to redefine themselves and reconstruct a new identity to reflect their altered position and way of being in the world (Williams, 1984). It is argued that much of a person's self worth and self esteem in measured in terms of their ability to do things (Willis, 1986). When this ability to do and be active is adversely affected through illness, then the person's self and identity are often diminished, resulting in a loss of self (Charmaz, 1983). Having RSI and being unable to do even 'simple things' had an adverse impact on sufferers' sense of self and identity. For example, one consequence of being unable to contribute to house work over a long period led to strained relationships, in which the sufferer felt others perceive her of being lazy, which had a negative impact on her self esteem.

Participant P0018: 44 year old female with RSI for 2 years and 3 m (Group 2)

*“I have had RSI symptoms for so long that all those around me think I'm a 'lazy good for nothing' – after all I now can't Hoover, wash the cutlery, do the ironing or any of my favourite gardening tasks (or even the unfavourite ones such as weeding!). I am constantly saying "ooh can't do that" and in fact am thoroughly useless at everything I seem to touch now! Even reading a book or magazine can bring on excruciating pain and as for writing..... or changing the beds.... or carrying anything remotely heavy (my hands are so weak I drop things constantly!).”*

Some sufferers said because of RSI their confidence and self esteem was at rock bottom level and they felt they were “on the scrap heap”. RSI changed sufferers' perceptions of themselves too from being a valuable member of work, society or

their household, and contributing to the financial income for the family or family roles, to one who is incapacitated and therefore less able and less valued. Because of experiencing pain and difficulty performing everyday tasks, sufferers felt their confidence had been destroyed.

Participant P0031: 35 year old female with RSI for 6 yrs and 9 m (Group 3)

*“...RSI has destroyed my carefully built up confidence. I used to be a pretty happy person most of the time. I feel that I've permanently lost that person. I had clinical depression in 2000 (as a result of being in permanent pain) and although I 've slowly recovered from that and am happier than I've been in several years, I still feel that it wouldn't take much to plunge me back. Any serious flare ups can really knock me. Although I tell myself that it will get better if I am positive, it can be very hard to be positive, particularly if it coincides with other sort of problems in work/ family.”*

This excerpt highlights how RSI has negatively affected this person's sense of self and continued to make her feel vulnerable. Her life seems to be precariously balanced in that although she is much recovered, she feels she could easily revert to her previous situation. Her personality had changed for the worse and felt she had lost her former happy self. Another sufferer said she had a constant feeling of 'why me' and had changed from being bright, bubbly and capable to fed up, miserable and being thought of as not up to the job.

Others around sufferers influenced their sense of self worth and had the potential to make them feel they had nothing to contribute without the use of their hands. One person described feeling “written off” when told by a local disability advisor that she was not very useful if she couldn't use her hands. In another situation an archeology student who experienced pain whilst digging during a field trip and had to change to lighter duties, expressed concern about what her friends and lecturers would think of her and wondered whether they thought she was just trying to avoid hard work or that she was weak. In the face of concern about what others thought of them, many sufferers portrayed themselves as hard working individuals, who were loyal employees who had given their best to their employer and who contributed to the community.

### 9.19.1 Finding positive meanings in negative circumstances

Although many of the changes due to RSI were adverse, some people were able to give RSI some positive meaning in their life such as understanding important things about themselves, (one person described this as a pleasant side-effect of having RSI). Others used RSI as an opportunity to re-evaluate and make changes in their lives, and an opportunity to pursue something they really want to do. Some felt RSI had made them mentally stronger through having endured a difficult experience. Others moved to find more enjoyable work or found satisfaction in being able to help others.

Participant P0015: 22 year old male student with RSI for one year (Group 2 France)

*"I've read on some web page: 'RSI won't end your life, but it will change the way you live it.' Apart from the pain, my RSI has proved helpful to my general well-being; for example, I get much more sleep now since I don't spend nights coding anymore :-). My social life has also much benefited from it. In that regard, RSI is actually quite positive as it made me rethink my whole lifestyle."*

One participant said his coping efforts would continue as he wished to make further changes now that he understood better how his mind and body worked. This included everything from reviewing the use of gadgets to rethinking his career. He felt he was a different and better person to the one at the start of his RSI so in this sense RSI had considerably changed his identity.

Many sufferers wished to share what they had learned about RSI to benefit others and felt that there would be some positive purpose to their suffering if they could in turn help someone else. Other positive moves were a move from the corporate world to finding more enjoyable work in a charity shop which didn't involve working with machines all day. Another sufferer who had made a full recovery from RSI said she was a little more delicate but a lot wiser and stronger in spirit than before. One sufferer said he had changed beyond recognition in that he had learned to be less fearful of what the future would hold and had become an optimist and started to enjoy his life, no longer worried about asking for help and being less worried about saying that he was unable to do something – especially at work. The Alexander Technique had changed him as a person beyond recognition. He had changed to



living in the present and not being fearful of the future and he tried to find a positive way out of any situation he found himself in. He had learned to manage his pain so that although pain was still part of his every day life, it was not the all consuming factor it used to be.

Another sufferer said that although RSI had changed her life completely - socially, domestically and as an individual, she felt some of the changes may have been for the better since she now listened to what her body was saying to her.

## **9.20 Theme 9: Life as an emotional rollercoaster**

RSI created emotional turmoil for sufferers with three people describing life with RSI as an 'emotional roller coaster'. The unpleasantness, intensity, unpredictability, persistence of pain together with uncertainty about recovery and the future made sufferers emotionally vulnerable and defensive. Feelings of anger and frustration were common arising from having long term pain, an explanation for which often remained elusive and the perceived lack of understanding of others. Sufferers' personalities changed due to RSI such that they considered themselves to make poor company for others since talk about pain dominated their conversation, and which they feared would bore others, resulting in sufferers avoiding social occasions and gradually becoming more isolated.

Guilt was felt about burdening other family members who had to assume additional responsibilities. Moreover, having to rely on others to do things for them instilled a sense of loss of control and freedom over their own body and life and a feeling of helplessness. One man described feeling uncomfortable about the strange looks he got from others in the supermarket when he stood empty handed next to his heavily pregnant wife whilst she pushed a laden shopping trolley. Since much of the emotion stemmed from pain, sufferers wanted relief from and control over their pain and a diagnosis to provide medical corroboration of its reality. Many sufferers became depressed because of their pain and their resulting situation.

One sufferer recounted a meeting with her manager in which she had tried to convey her feelings. She described her feelings as anger and frustration resulting from being unable to do things, embarrassment and pride over asking others for

help, fear of being on sick leave and withdrawing from others, fear of losing her job, skills and mind. She added that whilst she felt relieved at having told her manager this, these feelings only represented the tip of the iceberg. Occasionally negative emotions were directed at the injustice of wider society for which there were no easy answers such as illustrated in the excerpt below:

Participant P0028: 46 year old male with RSI for 7 years (Group 3)

*“Why does the system crap on the people who have worked hard all there lives, why do employers cripple their employees and sack them, why does the system then treat them like workshy frauds and liars, why are profits more important than people?”*

Other emotions mentioned were anxiety, fear and frustration from unsuccessful attempts to obtain a diagnosis and treatment, emotional upheaval caused by constant pain which was exacerbated by the lack of understanding from those around them. Uncertainty about recovery, future prospects and plans was a major concern for many. One individual said he got into a terrible mental and physical state from fear that he may never work again, or may not recover and the effect this would have on the family he and his wife were planning since his wife was pregnant and their plan had always been that his wife would give up work and that he would financially support the family. Letting go of these worries was important but difficult.

## **9.21 Theme 10: Changes in relationships**

RSI changed the dynamics of many relationships most notably family relationships such as between husband and wife in the home. Sufferers became more dependent on family members for help resulting in feeling helpless and guilty about being a burden to others and resentment at their own loss of freedom. This could be physical dependence on others for help from opening jars/bottles to relying on others to drive them places as well as being financially dependent on their partner and the consequences of this. Being unable to contribute towards family finances evoked feelings of guilt and some said they found it difficult to ask others for help. Many relationships became strained by the changed attitude of others towards sufferers and conversely sufferers changed their attitude towards others. Relationships could become fractured through being unable to share in household

chores. Moreover, changes to their personality could result in sufferers being more irritable, less tolerant of others and miserable, which could alter relationships. Some sufferers said they avoided contact with others for fear of boring them because of their incessant talk about their pain. Furthermore because of the difficulty in getting comfortable at night, some sufferers resorted to sleeping in another room, resulting in couples sleeping apart. Some relationships broke up but this was not widely discussed although underlying tensions in relationships were evident. Insights into the difficulties caused by long term illness can be seen in the excerpt below:

Participant P0018: 44 year old female with RSI for 2 years 3 months (Group 2)

*"...but my partner is desperately bored of my symptoms and finds me exceptionally annoying - and useless! He tells me to shut up 'cos he knows what I'm about to say - I'm a stuck record. If he catches me having a whimper upstairs he rants and raves at me to grow up, change my job, get an operation. Although I would appreciate his sympathy occasionally I sort of understand where he's coming from - it must be tedious to have someone whining away doing the most mundane of chores!"*

Participant P001: 54 year old female with RSI for 2 years 10 months (Group 1)

*"Finally, I HATE having to ask my husband for permission to buy something; I absolutely hate it. That's the worst thing, in my mind; the loss of financial independence. I resent it, and it does affect, is affecting my marriage."*

### **9.21.1 RSI fundamentally changes life**

From the wealth of focus-group data discussed above, we can conclude that the essence of the RSI experience is one involving a fundamentally changed and different life to the one lived prior to getting RSI and a changed future. Having RSI meant coping with significant physical difficulties and pain, financial hardship, strained relationships, emotional turmoil and fighting for medical validation and social recognition and acceptance of their suffering and of RSI as a legitimate medical condition. It also meant living with considerable uncertainty and stigma from having a condition in which a diagnosis remained elusive, leaving sufferers' pain medically unexplained, compounded by the disbelief and lack of understanding of others. For some it meant living in a liminal state where they felt ill but were not accorded benefits of the sick role due to the lack of medical validation. Sufferers'

experiences were heavily influenced by their social environment such as the workplace, the health service, their social networks and the wider social status and acceptance of RSI. Some living with long term RSI said that it was hard to imagine a life without it, as it had become a part of the social fabric of their daily lives and identity. These themes and sub themes are summarised in Table 9.7.

**Table 9.7: Themes and supporting sub themes developed from focus group data**

<b>Theme No.</b>	<b>Name of theme</b>	<b>Sub themes supporting main theme</b>
<b>1</b>	<b>Changes triggered by RSI onset</b>	<ul style="list-style-type: none"> <li>• Onset normalised/tolerated initially</li> <li>• Enigmatic nature of symptoms</li> <li>• Explanations for RSI (predominantly viewed as a mechanical and work related injury)</li> </ul>
<b>2</b>	<b>Seeking medical help for RSI</b>	<ul style="list-style-type: none"> <li>• Multiple meanings assigned to a diagnosis and interpretations of negative diagnostic tests</li> <li>• Unhelpful medical encounters during quest for diagnosis</li> <li>• Characterising doctors as 'good' or 'bad' and expectations of doctors</li> <li>• Apportioning responsibility for managing RSI</li> <li>• Building medical expertise/knowledge base</li> <li>• Treatment ineffectiveness and side effects</li> <li>• Complementary and orthodox treatment options used</li> <li>• Threat of compensation compromises medical care</li> </ul>
<b>3</b>	<b>Interference with functional activity/social roles</b>	<ul style="list-style-type: none"> <li>• Widespread disruption to all life roles</li> <li>• Adverse impact on ability to work and its consequences</li> <li>• Impact in the home shopping, cooking, driving, caring for self or others</li> <li>• Withdrawal from/reduced social activities</li> <li>• Spoils special occasions like birthdays/holiday</li> </ul>
<b>4</b>	<b>Managing /Coping with RSI</b>	<ul style="list-style-type: none"> <li>• Seek out medical interventions (see Theme 2)</li> <li>• Physical strategies devised to manage daily pain</li> <li>• Changed mindset/attitude towards life/work</li> <li>• Support from others e.g. peer support (see Theme 7)</li> <li>• Discovering turning points and making improvements</li> <li>• Managing stress /finding ways to de stress</li> <li>• Coping with uncertainty about recovery, future</li> </ul>

5	Issues related to legitimacy	<ul style="list-style-type: none"> <li>• Invisibility of RSI and its consequences</li> <li>• Being believed</li> <li>• Carving out a new self identity</li> <li>• Stigma and feeling judged by others</li> <li>• Lack of wider social acceptance/understanding of RSI</li> <li>• RSI not taken as seriously as established conditions</li> </ul>
6	Financial impact of RSI	<ul style="list-style-type: none"> <li>• Impact of unemployment due to RSI on individual</li> <li>• Consequences of reduced income on sufferer/family</li> <li>• Using savings for private care/treatment/supplements</li> <li>• Purchasing items e.g. car with easier steering</li> </ul>
7	Changes in need of support	<ul style="list-style-type: none"> <li>• Support important at home from family and friends</li> <li>• Medical support from health professionals desired</li> <li>• Workplace support from employers and colleagues</li> <li>• High value placed on peer support e.g. online support gp</li> <li>• Consequences of lack of appropriate/adequate support</li> </ul>
8	Impact of RSI on self and identity	<ul style="list-style-type: none"> <li>• Becoming ill (but which may not be medically confirmed)</li> <li>• Reduced ability 'to do' leads to diminished self worth</li> <li>• Reconstruction maybe difficult/impossible without a diagnosis to identify problem as real and medical</li> <li>• Threats to integrity from accusations of malingering, secondary gain or stigma of psychological illness</li> <li>• Positive effects on self identity from illness experience</li> </ul>
9	Life with RSI as an emotional rollercoaster	<ul style="list-style-type: none"> <li>• RSI creates emotional turmoil/upheaval</li> <li>• Frustration, anger, guilt, embarrassment, isolation, fear, pride, depression, resentment, burden</li> <li>• Emotions impact on relationships e.g. more irritable, less tolerant of others, tearful and emotional</li> <li>• Feel sense of reduced control over life</li> </ul>
10	Changed relationships	<ul style="list-style-type: none"> <li>• Relationship dynamics changed e.g. more dependent</li> <li>• Relationships strained from being unable to contribute</li> <li>• Viewed differently by others e.g. ill person/maligner</li> </ul>

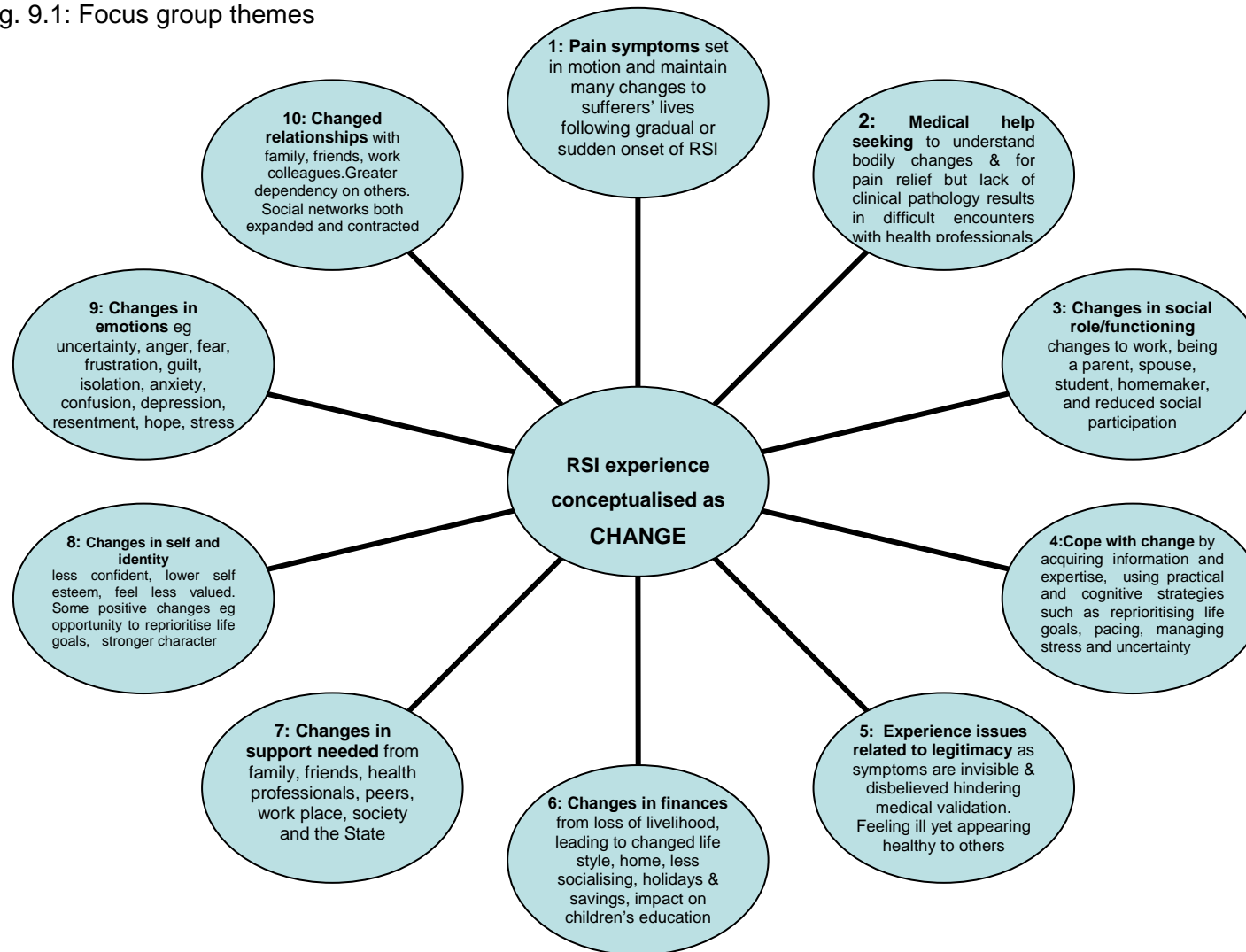
## **9.22 Clinical relevance of these findings**

This study highlights the importance for health professionals to be aware of how they communicate with sufferers, in particular the need to be sensitive to the interpretations sufferers may make of information conveyed and the negative impact that misunderstandings/misinterpretations can have on sufferers' self and identity and their ultimate recovery.

Whilst the majority of the impact of RSI on sufferers' lives was undoubtedly negative, some were able to reflect on their experiences with hindsight after partial or full recovery and ascribe some positive meanings to their illness experience. Whilst these positive effects were fairly low profile, this and other data suggest this is not an uncommon feature and there may be ways of incorporating this to help make cognitive and behavioural changes.

The search for an explanation and diagnosis of sufferers' symptoms is central to the RSI experience and is considered essential for moving forward with their illness. When sufferers were told no clinical signs could be found, this did not necessarily change their subjective experience of pain. Rather it intensified their need for a diagnosis and explanation which they needed to understand what was wrong with them and also to be able to communicate with others about their illness. Addressing this important need for a diagnosis or other suitable explanation is therefore a vital component of providing health care. Many of the treatments were perceived as ineffective, short term or had side effects. Both traditional and complimentary therapies were used with a desire for these to be integrated.

Fig. 9.1: Focus group themes





## **9.23 Summary**

This chapter covered the practical and ethical issues involved in conducting online focus groups, the reasoning behind the decisions taken and the processes involved in data analysis of the substantive content and group interaction.

Whilst online focus groups may not be suitable in every situation, the potential exists to capitalise on technology to bring together a group of people separated by distance in an online environment that encourages interaction and discussion. The themes which emerged from the data collected using this computer technology showed remarkable similarities to other chronic pain conditions indicating that it is potentially a useful method. Whilst there are some limitations in using online focus groups, there are many advantages for both participants and researchers. Findings from this study demonstrated that participants could be actively engaged in research over a 10 day period and that group interaction could be achieved to generate richly detailed research data.

The findings from both the e-mail and focus group study are next integrated to arrive at an overall conceptualisation of the essence of the RSI experience. This is considered next.

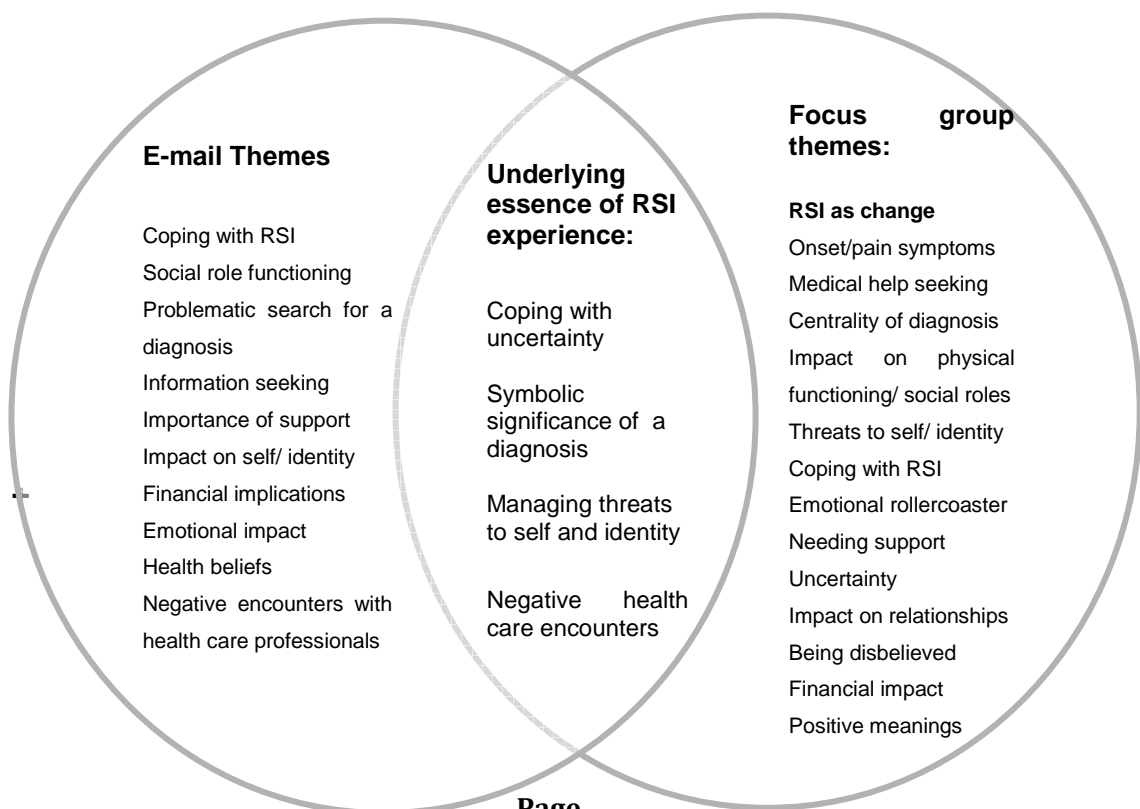
## 10 Chapter 10: Integrated discussion of research phases

### 10.1 RSI: The experience of illness without disease

As noted in Chapter 8 on phase 1 of the research, this study was an iterative process. The e-mail analysis led to the identification of themes which were then pursued in the focus groups. The rich data from the focus groups was then analysed to reveal the concept of change as central to the experience of RSI sufferers, as described in Chapter 9. Finally, the analyses of these two phases of the study were combined and the ideas which emerged from this integration of the data are now presented in this chapter.

The central themes identified from the two phases of the research into the experience of RSI are shown in the Venn diagram below. Common underlying features of the RSI experience are shown in the intersection.

**Figure 10.1: Underlying essence of the RSI experience**



The first point which becomes clear from the integration of the findings of the two parts of this study is that RSI bears all the hall marks of a chronic pain condition. This is typified by the issues which came through from both sets of data, such as long-term pain which caused widespread disruption to sufferers' lives, pain which could not be diagnosed or explained and was typically unresponsive to treatment, dissatisfaction with medical care and the lack of a firm diagnosis.

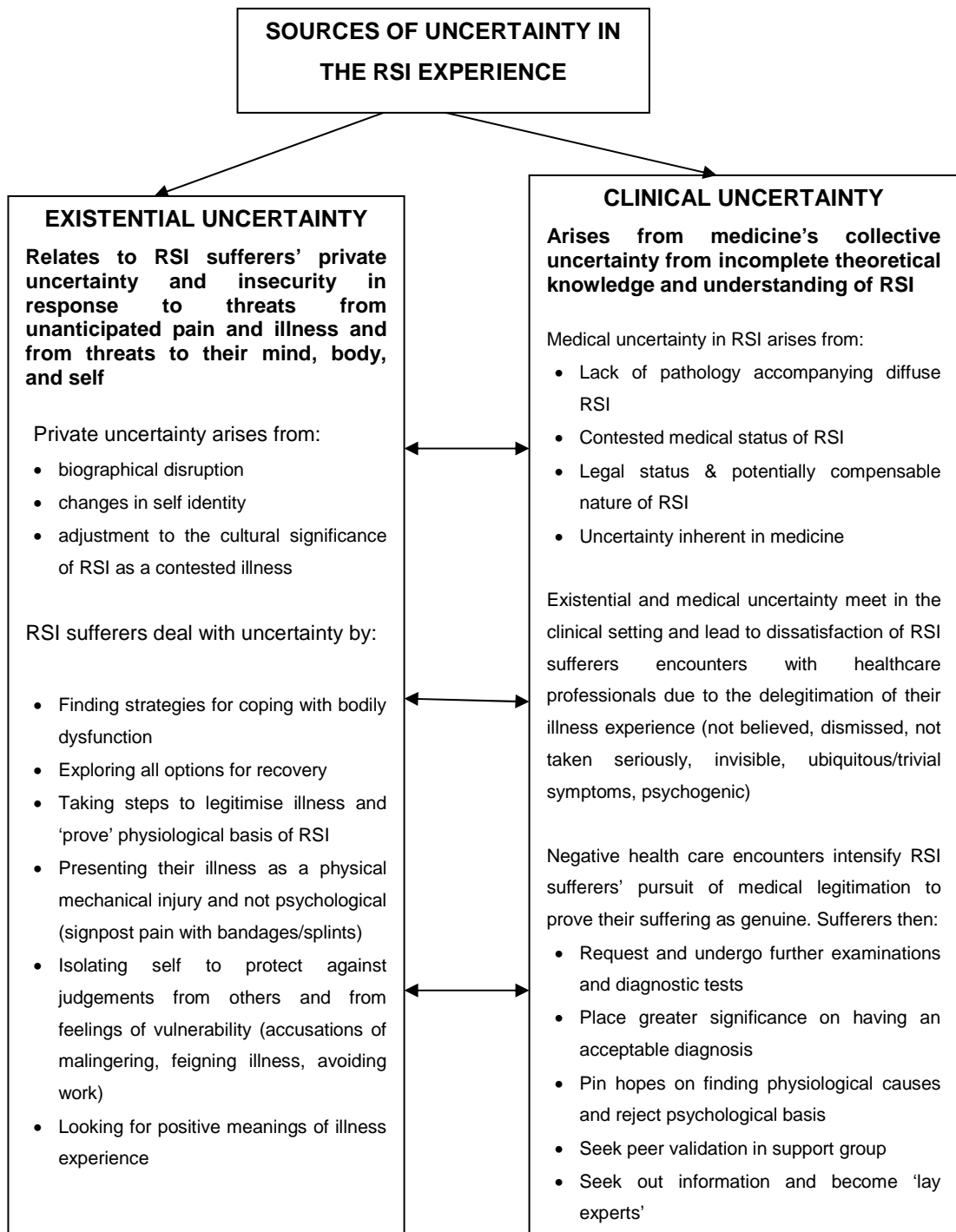
## **10.2 Uncertainty as a pervasive feature of the RSI experience**

In developing and integrating the common themes highlighted in the intersecting area of figure 10.1, it can be seen that uncertainty is a pervasive feature of the RSI experience. For instance, the need for a clinical diagnosis is far more important than just needing to know what is wrong; it is also needed to make sense of illness. The lack of a diagnosis presents and prolongs uncertainty which in some cases must be lived with for years. In an undiagnosed state, RSI sufferers exist on the margins of society where they feel ill but do not have the medical validation which ill people usually need to elicit help, understanding and support from others.

Mirroring the work of Adamson, (1997), RSI sufferers faced existential uncertainty relating to human existence in terms of how RSI illness would impact on their lives, how it would progress, their prospects of recovery and the timescale involved. RSI sufferers also faced clinical uncertainty from experiencing an illness without accompanying signs of disease, from having a disease which has an uncertain biomedical status and from the uncertainty inherent in medical practice. In RSI these two types of uncertainty were most apparent during the clinical encounter when sufferers expected to obtain answers about their condition, pain relief and a cure. However, instead they were faced with clinical uncertainty arising from doctors' limited scientific knowledge of RSI, its medically contested status and the nature of diagnostic procedures and practices. The attitude of health professionals towards RSI sufferers was a key factor in shaping sufferers' experiences as health professionals could intensify or alleviate RSI sufferers' uncertainty and worry about their condition. Conversely sufferers' uncertain symptoms could affect the attitude of

health professionals, some of whom disbelieved sufferers because they lacked clinical signs. The sources of existential and clinical uncertainties in RSI and the way they relate to each other are summarised and presented diagrammatically in figure 10.2.

**Figure 10.2: Sources of uncertainty in the RSI experience**



### **10.2.1 Existential uncertainty in RSI**

Existential uncertainty was pervasive in RSI sufferers' experiences and for many had to be lived with long term, together with the emotional distress and worry which accompanied their predicament. Uncertainty represented fear of the unknown such as what was happening to their body, what was medically wrong, not knowing what having RSI would mean, if and when they would recover, whether the condition would deteriorate or stabilise and when their illness ordeal would end. Sufferers had to live their lives despite unanswered questions about the impact RSI would have on their ability to work, their financial survival and when they might resume a life without RSI and pain. These factors increased uncertainty about the future which made it difficult to plan ahead or think optimistically about their future.

RSI onset presented uncertainty regarding the meaning and cause of painful symptoms and, over time, whether these warranted medical attention. Such uncertainty was tolerated for months or years by normalising or accommodating symptoms until pain did not respond to overnight or weekend rest, when seeking medical help became imperative. Corbin, (2003) stated that it was not until symptoms interfered with people's activities in a major way that they considered themselves to be ill.

The existential uncertainty faced by RSI sufferers in this study mirrors the findings of Adamson, (1997), who found that illness confronted people with threats to the mind, body and self which they had to contend with. In this study, in common with Adamson's (1997) biographical account of illness, ill people faced clinical uncertainty arising from the diagnosis, treatment, prognosis, physiological and psychological impact of the disease (Adamson, 1997). Some RSI sufferers in this study were unable to obtain a diagnosis due to the lack of clinical pathology. This left them feeling ill but without the benefits of medical validation, such as the sick role discussed earlier. In this study, uncertainty also arose from the low social acceptance of RSI due to its medically and legally contested nature. Having RSI also changed the nature of sufferers' relationships because of having to rely more heavily on others. Bury, 1988 (in Bury and Anderson, 1988) suggested that ill people have to renegotiate their relationships as these become altered during illness. The

findings from this study concur with the wider literature which highlights the important role of uncertainty in illness (Baszanger, 1989; Conrad, 1990; Adamson, 1997; Nettleton, 2006).

Uncertainty also has important implications for RSI sufferers' sense of self and identity as discussed in the next section.

### **10.3 Self and identity in this study**

In both the e-mail study and the focus groups, sufferers frequently felt disbelieved by others which negatively affected their self and identity. Dissonance between invisible painful symptoms located within the body and the appearance of the body as perfectly healthy to others, further compounded their suffering, in which their healthy exterior contradicted their inner suffering. Threats to sufferers' integrity arose from being thought of by others as lying, malingering and feigning illness for financial gain, exaggerating symptoms or having a psychological illness. The invisibility of pain to others made sufferers feel they were being morally judged as liars but had no way of proving otherwise. Comments from others such as "oh, but you look so well" were interpreted as others saying that they found it hard to believe that the person really was sick or else how could they explain looking so well. The stigma attached to RSI as a compensable condition, created further suspicion when no clinical signs of their pain could be found. Rhodes et al, (1999) stated that illness that was not visible or affirmed by objective signs threatened a crisis of meaning which most patients worked hard to resolve (Kleinman, 1988).

The invisible nature of sufferers' symptoms offered them the choice of disclosing or concealing their pain from others. This dilemma was most evident in sufferers' work environment where some individuals were reluctant to disclose RSI to an existing employer for fears of jeopardizing their job security, being passed over for job promotion or concern that others would think they were weak or disbelieve them. This dilemma was similarly confronted when applying for jobs when sufferers considered whether to disclose RSI to a future employer on job applications and at interviews for fear of discrimination and rejection. Some felt trapped in a lose/lose

situation feeling they could lose their job if they disclosed RSI, but on the other hand if they chose to conceal it, they would have to continue to work in pain and forego any employer help and support they might be given. Schneider and Conrad, (1983) similarly noted that patients withheld information about their illness from their employer for fear of risking their employment. Baszanger, (1989) stated patients' decisions to reveal or conceal pain depended on the balance between the social and emotional costs (e.g. feelings of shame or guilt) against the perceived benefits (e.g. access to health care, sympathy for their suffering and help in adjusting to pain). Kotarba, (1983) stated that chronic pain patients' decisions about whether to disclose or conceal pain depended on their particular subculture; the athletes in his study relied on the 'athletic sub culture' and the manual workers relied on the 'tavern culture'. However, Kotarba found that an over-riding consideration for both groups of workers was job security and fitness for work as the breadwinner (Kotarba 1983). The strategy of 'passing as normal' or concealing illness whilst helpful can make sufferers isolated from the reaction of others. Moreover, Conrad stated that concealing a potentially stigmatising condition cannot protect the self from the person's own doubts of competence and identity (Conrad, 1990).

Hilbert (1984) reported that illness was concealed to avoid burdening others, concern at annoying others with pain talk or because individuals did not want pity or sympathy from others. Disclosure also increased the risk of others making judgments about their condition, personal constitution or state of mental health (Hilbert, 1984). Illness was also concealed for fear of being disbelieved, pain being attributed to psychological causes, that claims of suffering were exaggerated, they were avoiding work, defrauding the insurance company, had a weak character or were using pain as an excuse for avoiding people they disliked (Hilbert, 1984).

Overt and visible distress were often the only means for pain sufferers to establish the legitimacy and reality of their pain to others, but in doing so they lowered their own self regard (Richardson et al, 2006). As noted previously, some participants in this study consciously sought to alert others of their illness by wearing medical symbols e.g. splints and bandages.

### **10.3.1 Male and female RSI experiences**

Although specific comparisons were not drawn between male and female participants' experiences of RSI as this had not been the aim of the study, the data suggested that male and female RSI experiences were broadly similar in terms of RSI having a major disruptive effect on sufferers' everyday lives both in and out of work, symptoms being disbelieved or attributed to psychological causes and depression resulting from pain and RSI. Furthermore, the study indicated that there were societal and personal expectations regarding the roles of men and women. For the male role for example there was pressure to be the family breadwinner and to provide for the family. In response to the same financial issue, females felt guilty at being unable to contribute to family finances. There were also indications of the difficulties in being unable to conform to expectations of masculinity, such as the expectation that the husband should be pushing the loaded supermarket trolley rather than his pregnant wife.

A further notable observation made during the recruitment phase was that male participants appeared to be more reluctant to volunteer to participate in the study than their female counterparts, despite indications that there were many male members in the discussion group. Owing to the low number of male volunteers who initially volunteered for the study, two additional recruitment postings were subsequently made specifically targeting male volunteers. Despite this extra effort, only 14 males took part in the study compared with 43 females. Also of note was the fact that three of the male participants in this study stated that RSI was probably more widespread in males than statistics would suggest. They each said that they knew of other males in their work environment who suffered with RSI type symptoms but who were reluctant to disclose this to their employer for fear of job security and were likely therefore to be a part of the larger hidden group of RSI sufferers.



### **10.3.2 Connections between self and identity issues in this study and in the literature**

The findings in this study relating to identity reaffirm the findings noted in other studies and for other chronic pain conditions (in itself a confirmation of the status of RSI in this regard). Charmaz (1983) and Bury (1982) suggest chronic illness forces a major re-examination of the person's biography and self-concept, and Williams (1984) argued that chronic illness required a "narrative reconstruction" in which a new identity had to be created.

As noted above, in becoming ill, the person's social identity changes from being a well and healthy person to being a patient and this echoes Frank's (1998) finding that illness creates discord between the physical, social and moral being. The resulting bodily dysfunction from illness necessitates a search for an explanation of cause of illness and makes individuals review their lives. Kelly and Field, (1996) suggested that the dissonance between the private experience of people's bodies and their social identity was what made the experience of chronic illness so distressing. Morris (1991) also stated that illness threatens people's different social identities such as their identity as a woman, homemaker, or a worker.

The findings in this RSI study are also consistent with Werner and Malterud's (2003) study in which women made their illness credible by presenting themselves as mentally stable by not looking too strong or too weak, too healthy or too sick, too smart or too deranged, and with Reid et al's (1991) RSI study, in which women presented themselves as not being one for sitting around. In these studies, women tried to present positive identities in the face of delegitimation. They presented themselves as hard working rather than malingerers or compensation seekers and as sane and in control and therefore suffering with a physiological condition and not a psychological one. They claimed they could cope with high levels of pain and try to assert normality through describing ordinary everyday events (Richardson, 2005; Werner and Malterud, 2003).

### **10.3.3 Implications of the identity issue for management of RSI**

Because, as this study confirms, RSI affects the perceived identity of sufferers so forcefully, it is important during their treatment that they see the identification of their condition as being specifically RSI, rather than simply 'another chronic pain condition'. Therefore, while clinically it is important to recognise RSI as a chronic pain condition, when dealing at the micro level with sufferers, it is important for them in personal as well as treatment terms, to see that the treatments and explanations they are being offered relate directly to their particular circumstances.

### **10.3.4 Positive impact on self-identity**

Whilst many of the changes accompanying RSI were adverse, in this study some sufferers found positive aspects from their illness ordeal which they were able to use. Examples included gaining a better understanding of themselves, using RSI as an opportunity to change career, to do something they really wanted to do, an opportunity to re-evaluate their own life style and life goals, to re-prioritise their own health and to help others with similar problems. Positive outcomes have similarly been noted in other studies. In Dorland and Hattie's (1992) study of individuals with RSI, 50% of RSI sufferers reported that they had found some positive outcome from RSI. Similar positive illness outcomes were also found by Asbring (2001, 2002). Frank (1995) stated that in the quest narrative, positive aspects from illness were found such as new insights gained from people's experience of illness which they could use to help others and appreciating that illness had social aspects as well as personal.

The biographical disruption experienced in illness involved both losses and gains which had consequences for identity. Asbring, (2001) suggested that biographical disruption in chronic illness could be positive as well as negative whereby sufferers had intangible illness gains such as changed values, insights into self and increased understanding of illness. Illness has also been suggested as a catalyst for change in social life (Ware and Kleinman, 1992), a concept which is the forerunner to the

broader theme of change identified in this study through the focus group analysis and discussed in chapter 9.

## **10.4 Clinical Uncertainty in RSI**

There are two aspects to this key concept:

- Uncertainty about RSI as a physiological or psychological condition and the implications of this for both medical practitioners and sufferers

and

- Uncertainty in clinical management of RSI as a result of no firm diagnosis.

### **10.4.1 A physiological versus psychological basis of RSI**

Clinical uncertainty in RSI arose from the ongoing debate about whether RSI had a physiological or psychological basis. RSI sufferers interpreted this as meaning that their condition was considered genuine and real if it was attributed to physiological causes or imaginary and unreal if it was attributed to psychological origins. In view of these beliefs, sufferers rejected a completely psychological cause for RSI although many acknowledged that stress may have been a contributory factor in its development. Hilbert, (1984) stated that one reason why chronic pain patients sought medical help was to establish their sanity. This is relevant for RSI sufferers since in the absence of a diagnosis, RSI was attributed to psychological causes which sufferers rejected. Having RSI attributed to psychological causes intensified sufferers' resolve to obtain a diagnosis which confirmed a physiological basis, and became the principal means of 'proving' that RSI had a physiological basis, consistent with their beliefs that RSI was a physical injury. Sufferers perceived a diagnosis would both substantiate their claims of suffering and simultaneously rule out psychological causes. This thinking perpetuated the mind/ body dichotomy underlying their beliefs and the negative connotations associated with a psychological cause. Ware, (1993) stated that in Western society signs and symptoms were interpreted as either bodily disease due to some identifiable biological malfunction, or as mental illness taking place in a disturbed mind. Ware,

(1993) stated that true illnesses were perceived as those which could be 'seen' in the body, whose presence could be verified from their objective physical signs and those which could be attributed to an underlying physiological structures or physiological disorder. Conditions which could not be linked to bodily abnormality were considered to be in the mind and discounted as not real (Ware, 1993).

The similar rejection of a psychological diagnosis has been noted in back pain patients (Glenton, 2003) and CFS patients (Ware, 1992), where an organic explanation carried greater creditability and had less stigma of mental illness attached to it. May et al's (2004) study on chronic back pain, found patients employed narrative strategies which reduced the risk of their condition being attributed to psychological causes. Similarly Werner and Malterud (2003) found that women with unexplained pain constructed their illness in a way which persuaded the audience that their pain was somatic rather than imagined. Nettleton found that whilst psychological antecedents to symptoms were resisted, the underlying fear that they might be psychological after all, "still haunted them" (Nettleton, 2006:1173).

In this study, sufferers were repeatedly told by health professionals that their pain was "all in the mind", an explanation which sufferers usually rejected. Sufferers routinely encountered health professionals who did not believe their symptoms were genuine because negative diagnostic tests had failed to reveal any objective markers of disease. In some cases sufferers were out rightly accused of malingering or lying or this was alluded to during consultations. Whilst the contribution of psychological stressors such as work pressure and poor working conditions were recognised within this group, to them, their symptoms were first and foremost an injury, often believed to be caused by or associated with over- use of the computer keyboard or mouse at work.

Despite negative diagnostic tests which revealed no signs of pathology, RSI sufferers' were resolute in their conviction that RSI had a physiological basis and remained undeterred in their search for a diagnosis. Sufferers in this study underwent numerous diagnostic tests believing optimistically that eventually one of them would elucidate the physiological basis of their symptoms. However, each diagnostic cycle entailed potential discomfort, uncertainty, emotional turmoil as well

as hope. This willingness to undergo further testing was found in other contested illnesses (Peters et al, 1998; Nettleton, 2006; Frank, 2001). A diagnosis was considered important because people found it preferable to say they had a named condition rather than symptoms without a name. Nettleton (2006) and Nettleton et al, (2005) said those who had been ill for a long time, simply wanted 'permission to be ill'. There was societal pressure for those with contested illnesses such as RSI to obtain a diagnosis. Nettleton, (2006) argued that "Society does not readily grant permission to be ill in the absence of disease" (Nettleton, 2006:1167).

#### **10.4.2 Uncertain diagnosis**

As we noted in previous chapters and earlier in this integrated discussion, the issue of diagnosis is particularly important for RSI sufferers. However, as clinicians accept the view that RSI is indeed a chronic pain condition, they may tend towards simply dealing with the pain of RSI. The findings from this study indicate that there are many important consequences for sufferers if they do not have a clinical diagnosis for their condition. In this respect, having a diagnosis may lead to any pain treatment being more effective as individuals may be more receptive once they understand what is wrong with them and can abandon the search for a diagnosis. Hence, providing patients with a diagnosis is more than simply satisfying a solution to one part of the clinical puzzle.

Some of the uncertainty surrounding diagnoses has been discussed by other authors. Fox (1988) attributes diagnostic uncertainty to the underlying clinical uncertainty inherent in medical practice in which scientific knowledge required to diagnose disease and predict its outcome, was incomplete. Adamson, (1997) stated certainty was a moral ideal since in reality current medical knowledge and theoretical understanding were imperfect. Furthermore, Fox, (1988) claimed medicine was not an exact science and clinical decision-making was based on reviewing the clinical options available and assessing the balance of probabilities, rather than on absolute certainties (Fox, 1988). Clinical decision-making therefore relied on practical and theoretical certainties and uncertainties, doctors' personal experience combined with textbook knowledge (Atkinson, 1995). The upshot of this

clinical uncertainty is that many people, such as the RSI sufferers in this study, have to live with uncertainty which pervades many areas of their lives.

Nettleton et al, (2005) argued that despite modern medicine's "ability to predict, detect, treat and manage illness", many patients lived with unexplained symptoms without a descriptive diagnostic label such as RSI, CFS and chronic pain (Nettleton et al, 2005). Furthermore she argued that the current social emphasis on finding solutions, restoring health and achieving certainty made it potentially more difficult for those who had to live with uncertainty and chaos. In fact, it has been claimed that increasing medical sophistication, order and classification has reduced people's willingness to tolerate uncertainty (Fox, 1980; 1988; Nettleton, 2006). Crawford, (2004) added that ironically it was the expansion of medical knowledge and technologies that exacerbated the insecurities they were supposed to allay.

As noted in the discussion on psychological vs. physiological symptoms, sufferers in this study underwent numerous diagnostic tests and medical examinations, with renewed hope each time that doctors would find something which had been overlooked or not revealed in previous tests. These diagnostic investigations were time consuming, emotionally draining and expensive, especially if they had been undertaken privately rather than on the NHS, as was occasionally the case. One sufferer had spent £700 of his own money to have an MRI scan in the hope that it would reveal some abnormal pathology. Given the large costs involved in diagnostic tests, questions have been raised about whether such extensive diagnostic testing can be justified, given the low probability of obtaining a positive result.

This undesirable in-between state of being neither ill nor well also applied to RSI sufferers who were unable to get a diagnosis, sometimes for years. This situation has been referred to as 'diagnostic in limbo' (Strauss and Corbin, 1985), being in a liminal state (Murphy, 1997; Jackson, 2005) or a state of anomie (Dickson et al, 2007).

### **10.4.3 Consequences of medical delegitimation for RSI sufferers**

RSI sufferers' inability to secure a diagnosis in this study meant they had to live with extended or permanent uncertainty in which they experienced illness without the presence of disease. Werner and Malterud, (2003) highlighted how uncertainty could become much more than just a 'temporary nuisance' to become a permanent aspect of patients' lives, during which time they had to live without a diagnosis or explanation for what was wrong with them, and consequently were considered neither well or ill.

For RSI sufferers in this study, an elusive diagnosis meant sufferers were unable to define their medical problem and explain what was wrong with them. Moreover, the lack of a diagnosis denied them medical legitimization since their symptoms and suffering could not be medically verified. This in turn denied them an essential social resource with which to communicate their state of health to others, to enlist the help of others, to negotiate their new social identity as an ill person and for their own recovery. This was very important given that RSI like other illnesses is always experienced in a social context and people need to talk about their health (Kleinman, 1980). In this study, a diagnosis was welcomed with huge relief, even if this came after a decade of repeatedly being told there was nothing wrong with them. In contrast, without a satisfactory medical explanation, RSI sufferers felt misunderstood, vulnerable and isolated since others expected them to have been given a diagnosis. For these reasons, the diagnosis in RSI became revered as the ultimate emblem of medical legitimization, which allowed sufferers to make sense of RSI, conferred medical legitimacy, made convincing others of the genuineness of their illness easier and opened up access to sick role benefits. A similar reverence to a diagnosis was given by chronic pain patients in Hilbert's (1984) study and in Reid et al's (1991) study of women with RSI.

Medical delegitimation is common in patients with chronic pain and medically unexplained symptoms such as RSI. For example, Ware, (1993) found CFS patients were delegitimised because diagnostic tests failed to reveal signs of disease, suggesting the individual was in good health and because of their physical healthy appearance which led others to assume their illness was psychosomatic or non

existent (Ware, 1993). Repeatedly having their experiences delegitimised and discounting CFS as a real illness, resulted in anger and self doubt regarding their perceptions and rationality and underlying concern that there maybe some truth in these psychological explanations (Ware, 1992). However, Ware, (1993) found CFS patients resisted a psychiatric diagnosis since psychological disorders were stigmatised. Given the difficulties such patients experienced in having their illness recognised, Dumit, (2006) described contested illnesses such as CFS, as “illnesses you have to fight to get”, since the lack of biological facts denied them recognition, health care and legitimacy. Dumit, (2006) stated that although doctors in Western medicine deemed who was sick or not, they were influenced by employers, the health care system or insurance companies as to what was medically covered. In Dumit’s (2006) internet study of people with CFS and Multiple chemical sensitivity, sufferers had to “prove” their illness and suffering through mobilising facts.

A major consequence of living with undiagnosed symptoms was that it limited legitimate access to the sick role and its associated rights and privileges (Clarke and James, 2003; Glenton, 2003; Ware 1992, 1993). Glenton, (2003) concluded that ironically dependence on medicine was prolonged precisely because patients were given no clear diagnosis, explanation or treatment. Moreover, Rhodes et al’s (1999) study found that when patients’ pain was attributed to an identifiable organic basis, they felt relieved and vindicated. Conversely those whose symptoms could not be diagnosed experienced a profound sense of de legitimisation, feelings of shame and guilt and felt their sense of self and social identity was threatened.

In summary, the findings from this study indicate that RSI shares many similarities with the general chronic pain literature, and hence RSI can be considered a generic chronic pain condition. This, and the pervasive sense of uncertainty inherent in living with the condition, has important implications for the management of RSI. In particular, a careful balancing act is required between dealing with the condition as a generic one, and recognising the need for legitimation and a sense of identity to be maintained for sufferers.



## **11 Chapter 11: Conclusions and contribution**

### **11.1 Conclusions**

Central to the experience of having RSI is the uncertainty relating to its meaning, impact on work and everyday activities, diagnosis, prognosis, treatment, course, duration, and recovery. A diagnosis was important in making sense of RSI and was found to be a central concern in the RSI sufferer's experience. When a diagnosis could not be made, the uncertainty resulting from this caused considerable frustration for both sufferers and doctors and created mutual mistrust. The lack of a diagnosis also had important implications for RSI sufferers' sense of self and identity since without medical legitimisation, sufferers felt their experience was not accepted by others or left doubt in the mind of others and made communicating their state of health to others problematic.

This study revealed that the illness experience of RSI was complex, often protracted, multi-factorial and shaped by social agencies including the medical profession, employers, legislative frameworks, governmental institutions as well as sufferers' social networks. For individuals, RSI pervaded every aspect of their daily lives often changing their lives and self identities permanently. RSI sufferers also faced uncertainty related to their medical treatment, which was often ineffective resulting in sufferers broadening their treatment options to include alternative therapies. Coping with and managing enigmatic pain was a major concern together with procuring a diagnosis which was considered the ultimate emblem of medical legitimisation, essential for negotiating their new social identity as an ill person and for obtaining the accompanying sick role benefits. RSI sufferers' experiences involved the complex interplay between biological, psychological, cultural, occupational, legal and medical factors. The attitudes of others including health professionals, employers and wider society were key factors in shaping the RSI experience. All these inter-related factors have implications for both the clinical and occupational management of RSI.

In contrast to some of the earlier studies which focused exclusively on females, often in low paid employment, this study sample included males with RSI as well as females, many of whom were well paid white collar employees working in the IT industry, such as software developers or consultants as well as many university employees including academic and research staff. Also represented in this study were professional musicians, health care workers, manual workers as well as a number of self-employed participants. A wider age range was covered in this study than in Reid et al's (1991) study in which most of the women were over 40. This study included several participants in their 20s and some who were still studying and had not yet engaged in the world of work. In contrast to Reid et al's (1991) study where the women had left school at 15, as can be seen from the information above, this study included some highly educated individuals, including several people with higher degrees.

This study revealed the precariousness of RSI illness and the uncertainty and change it brought to people's lives and the range of emotions evoked by illness. It also provided insights into some of the less observed realities of everyday living with RSI such as the strange looks a young RSI sufferer received in the supermarket when he stood empty handed next to his pregnant wife who was pushing the supermarket trolley, or wishing that life would return to being 'normal' as gauged by receiving 'daft' Christmas and birthday presents such as Homer Simpson socks rather than practical gifts (books, equipment, pilates video, considered more useful for their RSI) which in the process had turned a special occasion into a further reminder of RSI.

From the distress of a mother in pain unable to change a nappy or that of a father being unable to hold his new born baby, each feeling disappointed at being unable to fulfill their parenting roles as they would have liked, to being unable to keep pace with other family members on holiday and feeling guilty about spoiling the holiday for them, RSI evokes a roller coaster of emotions.

Despite these differences in samples of RSI sufferers from different countries and a time difference of over a decade, the experiences in this study bear striking resemblances to Reid et al's (1991) study of RSI in Australian women. Moreover,

the RSI sufferers' experiences in this study also shared many similarities with sufferers of other contested conditions such as fibromyalgia (Henriksson, 1995) and back pain (Osborne and Smith, 1998; Rhodes et al 1999; Walker et al, 2006).

A particular feature of this study was the emergence of positive aspects being salvaged from the predominantly negative experience of living with RSI.

In conclusion, sufferers' experiences of RSI in this study highlighted how major changes to their lives, circumstances and identity were brought about by having RSI, many of which were shared with other chronic pain conditions. Underlying these major changes was the uncertainty and with it the fear of the unknown that they faced. Central to dealing with illness was managing some of this uncertainty by obtaining a diagnosis. This enabled sufferers to establish what was medically wrong, give meaning to RSI and a place in their lives, enabling them to move forward. Moreover in this study, achieving a clinical diagnosis was synonymous with medical legitimisation and acknowledgement of their problem. However, the practical realities of obtaining a diagnosis were difficult for those with diffuse RSI since they lacked objective signs on which clinical diagnoses are based. For these individuals the dissonance experienced between suffering illness symptoms without clinical evidence of disease, was a major factor in their pre-diagnosis experience and resulted in unsatisfactory medical encounters. It led to an unremitting search to obtain a diagnosis in efforts to gain legitimacy and prove their condition as real and physiological.

A diagnosis in this study had multiple meanings and uses; establishing sufferers' medical problem, eliminating uncertainty, conferring medical legitimacy and confirming their pain as real and physiological rather than psychological and imaginary. Individuals with diffuse RSI who were unable to achieve diagnosis had to contend with the dual burden of enigmatic pain symptoms and the social stigma arising from a condition which defied medical legitimisation. RSI sufferers experience was one of illness in the absence of disease and could mean living without diagnostic closure and ongoing uncertainty for years and decades.

The findings from this study also highlight the important role health practitioners have on RSI sufferers' experience of illness. Clinicians need to be aware of the multiple meanings a diagnosis has for the sufferer, particularly in the context of their daily lives where those ill need to tell others about their state of health. Explanations given to sufferers need to be couched in terms which are understood and will be accepted by them. There also needs to be sensitivity to the social impact that having a psychological diagnosis can have on sufferers' identity and lives and to understand why such a diagnosis might be rejected. The manner in which information is conveyed to patients is highly important since as strongly demonstrated by this study, patients and health professionals do not often find the common ground needed to build a therapeutic relationship. A convincing and satisfactory explanation needs to be given to RSI patients where a diagnosis is not possible, to enable patients to give RSI a place in their lives and to be able to move forward with their lives despite pain and the lack of a diagnosis. In addition, the manner in which information is conveyed to patients is just as important as what is actually said. The need for clinicians to be sensitive to the impact of the information provided to sufferers is paramount, since the way in which it is delivered affects greatly the way in which the patient receives and interprets it, accepts his or her situation, adheres to treatment regimens and ultimately moves towards recovery.

## **11.2 Contributions made by this study**

This study has made research contributions in the following ways:

### **11.2.1 Extension of knowledge**

This study has extended our current limited knowledge on the illness experience of men and women with RSI. No other comprehensive study has been conducted in the UK focused solely on understanding the holistic experience of having RSI from the sufferer's perspective. The two principal studies in this area were conducted over a decade ago. Moreover, no studies to date have used internet technology to understand the individual's experience of RSI although such studies have been conducted on other contested illnesses such as back pain, FM and CFS.

### **11.2.2 Methodological contribution**

This study has made a methodological contribution since illness experiences of people with RSI were obtained through the use of developing internet technology which is slowly adding to the repertoire of methods available to the qualitative researcher. Whilst many studies have analysed archived e-mails, very few have conducted interactive research in online focus groups involving recruiting members of the public and guiding them into a private password protected site hosted on the university website.

In addition, the analysis of archived e-mail presented ethical dilemmas regarding the obligation to obtain informed consent since there were very polarized views on this, making it difficult for new researchers. The model used in this study has now been published.

This study also highlighted the importance of interaction in online focus groups and how this can be assessed using a framework of questions to make it more tangible. This work has also been published.

Other research students within the university have subsequently conducted internet based research, benefiting from the practical experience developed during this research study.

### **11.2.3 Theoretical contribution**

This study affords an alternative conceptualisation of the experience of RSI in terms of one key factor which underlies and contributes to sufferers' holistic experience of RSI which is uncertainty. Sufferers are viewed as having to manage uncertainty related to the direct impact of illness which threatens their body, mind and self identity and the related but separate uncertainty associated with their medical condition. This medical uncertainty stems from the ambiguous status of RSI as a

pseudo disease which may or may not exist, medical uncertainty in terms of what diagnostic tests can tell us and how doctors reach clinical decisions. These two types of uncertainty were found to be inter-related and most evident during encounters between sufferers and health professionals.

#### **11.2.4 Practical contribution**

At a practical level this study has clinical relevance in highlighting the importance of how information provided by health professionals is interpreted by sufferers, what it means to them and how they respond to it in terms of their illness experience. It also suggests the importance and significance of a diagnosis to the individual, despite the fact that from a clinical standpoint a diagnosis may not be important or necessary for managing the condition. This study suggests that the lack of a diagnosis/acceptable explanation means RSI sufferers find it difficult to understand what is wrong with them and may be an obstacle in their recovery.

This research is of most use to health professionals responsible for managing and treating RSI since sufferers' views about diagnosis may be significant factors in affecting their recovery. Health professionals need to be aware of how what they say and how they say it will be interpreted by sufferers and the potential consequence of this on sufferers' recovery. The absence of a meaningful diagnosis or explanation has a significant impact on sufferers' sense of self and identity, since without an adequate explanation, sufferers may be unable to make sense of their illness and hence give it a place in their life. Whilst applying generic approaches to the management of RSI as another chronic pain condition may be logical from a clinical perspective, any such approaches must be tailored to RSI sufferers' personal circumstances, since treatments may be less effective if sufferers do not perceive the interventions as being specifically targeted at RSI.

Even in cases where a diagnosis is not possible, finding ways of explaining the condition in the absence of a diagnosis would be helpful to sufferers. As the ample literature on doctor-patient encounters demonstrates (May et al 2000 and 2004; Adamson 1997; Broom and Woodward, 1996; Asbring and Narvanen, 2003), the

frames of reference used by patients and health professionals differ considerably but this disparity needs to be reduced if patients are to be managed more effectively. This study suggests health professionals are key stakeholders in shaping the RSI sufferer's experience. Their interactions with sufferers can either exacerbate the uncertainty and insecurities arising from having RSI, by for example not believing sufferers, dismissing symptoms or attributing RSI symptoms to psychological causes. Conversely health professionals can mitigate sufferers' experiences by offering hope and motivating them towards recovery by acknowledging their symptoms, providing a clear explanation which is consistent with sufferers' symptoms and suggesting tangible solutions to improve functionality and to restore activities such as those advocated by CBT approaches. This study suggests that providing a tailored explanation that takes into account sufferers' individual experiences is important in helping sufferers move forwards with their recovery.

This study is also useful to those wishing to embark on internet research since the model developed may help other researchers.

### **11.3 Further work**

This research opens up a number of possibilities for further work. Whilst this study provided insights into sufferers' views, it would be useful to explore the views of other stakeholders such as employers or health professionals. A recent report by Burton et al (2008) suggests RSI is better managed within a biopsychosocial framework which requires more coordinated efforts between the occupational setting, healthcare and the individual with RSI. This makes it important to better understand the views of all parties concerned.

## **11.4 Limitations of this study**

Only a segment of the population uses the internet and support groups so the sample used in this study is biased towards those individuals who have internet access, can read and write and are computer literate. With the e-mail study it was not possible to verify details of people on the list and so the data was taken at face value assuming people were honest. Paraphrasing the e-mail quotes rather than using direct quotes may also have led to a less direct account of RSI sufferers' experiences, as the researcher had to interpret sufferers' words as it had not been practically feasible to obtain informed consent. Participants in the study were self selected so background information to screen people was unavailable and there was no way of confirming which diagnoses sufferers had been given, by whom or any other confounding factors. It is further argued that any type of support group is a biased sample.

In the discussion list used, those who recover from illness often move on, so the accounts obtained are dominated by those who are still struggling with their illness, meaning there may be fewer examples of positive experiences. The list therefore may not have provided insights into the experiences of individuals with mild symptoms, those who do not seek medical/social support and those who have recovered from RSI and moved on.

Some aspects of sufferers' experiences may not have been openly aired in the groups. For example Ambler et al, (2001) reported 73% of chronic pain patients experienced difficulties in sexual relationships based on their survey of 237 individuals. In an internet study by Murray and Sixsmith, (1998) on prosthesis users, they found participants were willing to discuss their sexual relationships in their internet study. However, sexual relationships were little discussed in this study. This may have been because the researcher did not explicitly ask for these or people were unwilling to discuss this in the open forum of the internet.



However this community provided useful insights into RSI experiences of people coming to terms with and currently living with RSI. Kitzinger, (1995) advocated that if seeking improvements in a service or situation, it was valuable to speak to those who have had negative experiences of the phenomenon and therefore people with this RSI experience were deliberately recruited to the study. Baszanger, (1989) for example deliberately sought a sample of patients with severe chronic pain on the basis that they were best placed to identify important problems and issues related to chronic pain.

#### **11.4.1 Critique of internet methods**

In comparing the two methods used in this study to access illness experience, it was seen that both methods highlighted similar data and themes largely overlapped. However, the difference lay not in the presence or absence of themes but in the level of detail which was generated to support and elaborate those themes. The data from the focus groups was much richer than the e-mail data. As well as the differences in the richness of the data, there were also personal differences from the researchers' perspective in terms of the degree/level of emotional involvement with the participants and the study. The researcher felt emotionally detached during the analysis of e-mails and considered her role was as a distant observer. The process of acquiring pre-existing data on sufferers' experiences felt one-sided since there was no direct contact with participants and the researcher played no part in data generation and had much less knowledge of the context in which the data arose.

This experience differed markedly from that during the focus group study in which there was a much greater level of involvement with and emotional attachment to the participants. Communication in the focus groups felt distinctly two-way in which good rapport was developed with the group (and between group members).

#### **11.4.2 Interaction within the groups**

High levels of emotional involvement, support and empathy were shown within the groups which elicited rich data demonstrating the value of this method. The researcher was also able to update participants about other RSI research currently being conducted which participants said they found reassuring.

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## **Appendix 1: Reflexivity in this research study**

Introduction: what is reflexivity and why is it important?

Accounting for reflexivity is an important aspect of ensuring the quality of a study (Guba and Lincoln, 1985). Reflexivity recognizes that the researcher is influenced by his or her education, training, and background, which needs to be explicitly stated (Bryman, 2004). The researcher's position as researcher-as-instrument (Guba and Lincoln, 1982) further influences data collection and analysis. This information is important because what each person "sees" depends on their interests, biases and background, their theoretical stance and personal preferences (Schwandt, 2003). Reflexivity then refers to critical self reflection about one's biases or factors which may prejudice the researcher's judgment (Schwandt, 2003). Although being conscious of biases does not necessarily eliminate them, through reflexivity, they can at least be accounted for. Therefore in this section I will try to examine how my presence affected the research setting, process and what I observed, as advocated by Patton (2002) and others.

Pros and cons of a non-clinical background

Approaching this research topic from a non- clinical or pain background meant having to master many new areas of study and learn a vast amount of discipline-related language previously unfamiliar to me in sociology, psychology and on the ethics of internet research. On the plus side it afforded me the opportunity to learn and assimilate a vast amount of information which helped me to take a non clinician's perspective of the topic.

Prior knowledge of study topic

I had a negligible level of knowledge of RSI prior to my efforts to identify a suitable research topic for my PhD. I did not personally know any of the participants prior to the study. My only personal connection with anyone with RSI was a neighbour, who

was a retired journalist and a keen pianist who had de Quervain's disease. However during the course of my project I have come across many people with RSI. Given my little knowledge of RSI before this study, the e-mail study was felt to be a good way to learn about both people with RSI and become familiar with the online environment before progressing to the online focus groups.

### How my thoughts developed during my study

I do not have a background in a health profession or pain research. Thus the move into health care research was both a unique opportunity and a considerable challenge. Fortunately I had a genuine interest in both the research topic (and in people) which has grown exponentially during this project.

Through the project my thinking developed and has followed periods of immersion in writing and revisiting the data and thinking and trying to link the two. Research articles read early on in the study whilst important, did not appear to hold major significance until much later when my own understanding had developed sufficiently to appreciate what was being said and I was able to link this to my own research observations.

My early concerns over being disadvantaged at not having a clinical background were subsequently turned into a positive thing as it meant being free to "see" the problem from my own perspective rather than a clinicians.

### Interview status

My intentions in the focus group study were to give voice to the participants of a relatively under- studied group of people through investigating their accounts of illness experience. I considered the research process a collaborative event in which my own and participants resources were combined in a joint effort to obtain a better understanding of RSI.



## **Appendix 2: Examples of focus group data**

### **Participant JC45**

Hi All, I live in New Zealand where RSI is known as OOS (occupational overuse syndrome). However, don't be misled by the name. People who have OOS are usually treated like criminals here. We have a so-called universal insurance scheme which actually means that you can't take your employer to court for injuring you and you will also find it difficult to get insurance cover. The battle is continuous.

I got OOS at the library I worked at. Out of a staff of about twelve full-time equivalent, three came down with it severely within a space of a month and only one staff member did not have it at all. She worked one morning per week. It is a good example of how OOS can be proven to be work-related, particularly as the injuries nearly always occurred when working rotating books at the rostered discharge/issues desk. Suffice to say that staff overload and bad ergonomics, plus not monitoring the fact that some staff were doing twice the amount of book rotation movements than others, led to some of us being very severely affected. The attitude of our employer was terrible (a city council) and I was suspended for serious misconduct and finally dismissed. One lady from that library still cannot lift her arms after 6 years and her husband often has to feed her and dress her. I was like that for some time but now am doing some papers at university, with a notetaker to take notes for me. I also have an automatic car now



which has given me a lot more independence.

OOS/RSI has affected every area of my life. There is not one area that it hasn't. This fact is not well appreciated by many doctors who think you just have a little ache. It's definitely not a little ache.

## **Participant QS52**

Hi my name is X. i am 30 years old and have suffered from RSI for the past 2 1/2 years. I was diagnosed with De Quervains Tenosynovitis 2 years ago. Over the past few years i have been thorough the good the bad and the extremely ugly days with by batter against RSI. I have hit rock bottom and recovered, althought my sypmtoms have never gone away, i have learn't to cope. Today i have been accepted onto the St Thomas's INPUT course which as you are all no doubt aware is a residential course either 4 or 2 weeks in duration. I'm not really sure how i feel about this at the moment, as its ultimately the end of the line, when it comes to hospitals and referrals.

Over the last few years i have had over 60 hospital appointments, with the likes of Rheumatology, Pain Clinic, Pain Management, Occupational Therapy, and various other consultants along the way. I'm sure by now i could quite easily write a book on my RSI (my union recommended i kept diary, which i did, so technicall i have and its a riveting 50 pages of me and my RSI) exciting not!!!

Anyway thats me in a nut shell.

## **Participant RD28**

Hi I'm....

X - I'm currently working as an eBusiness consultant for a large bank which means I do lots of work with web sites - design and development but also lots of maintenance. I've had problems with my shoulder for a year or so. Prior to that I had sore forearms when I was writing my dissertation for my degree which have now cleared up and in retrospect were as much psychologically stress related as physically.

The shoulder pain: It's like a tingling/buring pain in my upper arm/shoulder which gets worse as soon as i start working now! I've had lots of physio and now have A.Technique when I can afford.

From all the reading I have done it seems shoulder prb.s are to do with posture but despite all my attempts to improve it the pain is still there.

One of the most depressing aspects of this is I used to play alot of drums and recently (last year or so) I play less and less - partly because of the pain but also confidence has gone because of the pain also.

Thats all I can think to write at the mo'!

Cheers

## **Participant KA21**

My name is X. I'm 28 and working for the nhs doing research and information support along with providing some IT support and development for my dept. During the winter of 1999 I was working on a university web site which meant using a mouse pretty intensively. Pains developed in my right arm and after I switched hand in my left. These were a combination of burning sensations along the underside of my forearms and kind of bruised feelings in my upper arms and more acutely across the top of my hands. As these got worse I raised the issue to no serious response. The pains would not rest and some tingling pins and needles feelings developed along with loss of grip, causing me to crash my bike as I cycled home one day.

The first doctor I saw was dismissive and told me that all workers get tired and need a break from time to time. The next, a sports specialist, was more sympathetic, though cautious of legal entanglement, and diagnosed Tenosynovitis. I finished my contract with the help of a typist and was then mostly unemployed for 6 months. My doctor could not offer any solutions except the obvious so I avoided using computers and the rsi gradually stopped hurting. At first it was uncomfortable holding books open or dialing phones. Self doubt fueled by general scepticism and lack of support led to a lack of confidence in presenting my problem and I basically tried to work it out myself with no direct support.

Since then the problem has always returned pretty quickly as soon as I start using mice, though I have not

let it get like it did the first time. It is the microswitch buttons which particularly irritate so I've spent a lot of time, and money, investigating alternative input devices as well as modifying standard mice with foot switches and handles. I have taken Alexander lessons and try to keep reasonably fit. I have investigated ergonomic working methods and I use some of stretches that I've found and have changed my setup as best I can. An ergonomic workstation looks like it's outside my employer's benevolence, as with most I guess, especially given that it might take several attempts to find the best setup. At the moment I use a Cirque glidepoint for click-free 'clicking' along with either a 3M or vertical mouse, all supplied by me. I also use a split keyboard which I like a lot. The mouse keys option on windows has been very useful too as have keyboard shortcuts. So far all alternatives are much slower than mice.

Perhaps foolishly I have not given up on a computer using lifestyle. I hope and usually believe I'll find a way around it. I've got somewhat towards this goal, however I am now using them more intensively than in any period since the problem occurred and the increasing discomfort led me to find                      and join this group.

### **Appendix 3: Email data samples**

Participant MAE1

Subject : Re: Laptops?

Hello everyone,

I'm a new addition to your list and I have found all the recent e-mails fascinating reading.

I have had RSI for nearly 9 years now and use Dragon Naturally Speaking version 5.0 Preferred now on both my desktop and laptop machines. I do not use a keyboard at all apart E1 from switching the machines on /off the rest of the work I do by voice only. Has anyone else used the Naturally speaking products and if so how do you find them?

Participant HIE1

Subject : Re: Carpal Tunnel query

Hi X

I had both wrists operated on approximately 12 years ago with tremendous success. I had been advised before the operation to use some exercise grips to strengthen up my wrists, I think this really helped as within six weeks I was back at my work as a joiner. The scarring on my hands was really bad, the incision in the palms looked as if it hadn't been stitched at all, but this was simply because of the hard skin and soon healed to becoming almost invisible. but sadly after about three years the symptoms started to re-appear, very slowly at first but eventually becoming much worse than ever before, most of the information that I have acquired via the internet books and magazines give the operation a very high success rates. But

several reports that I have read state that the operation will only be a long-term success if the patient does not return to what caused the carpal tunnel in the first place.

The surgeon who carried out the first operation does not seem to think that a second operation would be successful, and has now referred me on to a neurologist's, if anyone has had similar trouble or even a second operation I would be grateful for their opinions.

As I cannot type any errors can be blamed on ViaVoice

Yours X

Participant GSE2

Subject : Re: Acupuncture

I have had acupuncture for tenosynovitis when I was having a bad flare up. It worked very well for me at reducing the inflammation and thus the pain. I have also had it in the neck area for pain in my upper arms. It worked brilliantly but unfortunately the effect only lasted a week.

It was done by my osteopath who I have a lot of trust in and I think that probably contributes to its effectiveness. He did say that it doesn't work for everyone - luckily it worked for me and simply knowing that it is available if the pain is very bad, helps me. However, my local GP also does acupuncture, so it might be worth asking your local health Centre. You'll have to wait a fortnight for an appointment of course (but that's another matter).

Participant WAE5

Subject : Re: rsi

I'm confused. Are we talking about supports that you wear (i.e splints) or the supports that go by the base of your keyboard?

In the case of splints, I'll agree with X. Only wear them on the advice of a health professional, and then for a limited time period. My physio got me a splint to wear for a few weeks, and I'd say that its main effects were a) reminding me not to do daft things with my right hand and b) convincing my colleagues there was something "properly" wrong with me.

As for keyboard wrist supports, I suspect this is a one-size-doesn't-fit-all issue. In my old job, I chucked my expensive, gel-filled wrist support out, because it seemed to be making things worse. Currently, I use a cheap foam version, given away by a drug company, which seems to help. I guess the main difference between the two is that my current wrist support is curved, rather than squared off, in profile and is given to slipping round if you put too much weight on it, which helps prevent slouching.

good luck finding something that helps

Participant TCE22

Subject : Re: New route to investigate (long)

X - There's actually quite a lot out on the net (UK too) about fibromyalgia. As far as I know it's well recognised, certainly I've seen books in the local library on it, and rheumatologists should be well aware of it. There are specific diagnostic criteria for it to be applied, but if you don't meet them there's also myofascial pain syndrome (a kind of catch all/doctor doesn't really know what else to call it when you don't quite meet all of the diagnostic qualifications for FM but exhibit generalised muscle pain and related symptoms).

The site to which you refer is a US one and like many things there is very keen on promoting it's miracle cure and theory that explains everything - not to say that there isn't something in it. I think it's the same tack as quite a few US docs are taking at the moment, amongst them Travell and the trigger point lot. I

note interestingly that he's saying that FM, MPS, CFS and many other things are really all the same condition. I tend to take such sites with a pinch of salt, although a lot of what he says rings very true - but hey, if it works for you then go for it. He's got as much right as any other scientist/doctor at the moment, because I can't see that any of them have the answers yet.

I came across FM quite a while ago in my researches and on the quiet have long suspected that many of us with "RSI", especially the diffuse type, are also suffering from FM/MPS to some degree or other, or at least symptoms that come very close, by whatever name you wish to call them. But, whether caused by/as a result of the original RSI or as an underlying separate problem aggravating the problem, I don't know. Neither, I suspect, do the doctors.

My pet theory (totally unqualified but from experience) as it involves RSI (of one particular type anyway, bearing in mind that RSI itself covers a multitude of conditions) is that the FM needs a trigger to start it off (like the initial RS Injury)- from whence it becomes irritable muscle syndrome combined with various other bodily complaints stemming from this constant onslaught on the poor old body (or simply stress - it also seems to be stress linked, as is RSI.) It might all be one great big circle. Perhaps diffuse RSI is actually MPS by another name, but one with a known cause (work related/computer strain). Maybe we need to treat both the FM/MPS and the RSI itself at the same time (wot - the NHS treat two co-existing conditions? Flock of pigs flaps its way lazily over...)

I certainly feel that since I started using computers I have not only had the precise/locatable pain but a growing general malaise and muscle tiredness/pain, loss of stamina (etc) which I associate with the same thing - many of my symptoms fit into the FM/CFS diagnosis, but others definately don't and are physically detectable/causable. For instance I don't really have the 11/18 pain points, nor the overall body pain - my pain is located to upper back and neck, mostly one sides and definately linked to the way I sit and when I use the desk and computer at work - but otherwise it does feel as if I have FM from general body fatigue and other symptoms. Maybe it's really MPS - but then again, if you have a muscle (or whatever )injury and are straining to work in a tiring pose and are in pain,



wouldn't you expect that to cause similar symptoms too?

Not to de-bunk this at all, and it certainly is a genuine condition for some, but isn't the trouble that if you have a genuine work related injury it's very easy to use FM as an underlying medical condition to take the heat off the employer to some degree? And I think most of us with RSI are pretty convinced that it's something related to our work that's put us in the boat. I know that the pain is brought on by what I do and how I sit/work at my job – I also know I never had it before I started using computers at work. I can go with an FM predisposition theory as it at least explains why some people doing the same job get RSI and others don't - but then again, there's other explanations too... I can go with RSI causing FM or similar symptoms of generally annoyed (bits or all of) body and then being hard to throw off - but I can't go with FM being the whole answer or the whole cure if you actually have an injury/trauma - which is, of course, what RSI is. Personally I think it's fairly easy to tell the difference by looking at cause and aggravation of symptoms.

To be practical, rather than trying to pin some medical disease label on it in the hope of a desperate cure, one reason why perhaps quite a few of us aren't getting better (well, me certainly) is simply because our work conditions aren't improving and we carry on doing exactly the same thing day after day and abusing our bodies and wrecked muscles/tendons/nerves/necks/wrists instead of resting and letting problems and stressed/exhausted/pain wracked bodies heal and recover. I always feel that if I could stop doing what causes it (i.e. if work didn't hurt!) then it's OK and I'll recover - whether or not I have some underlying illness/disability or not doesn't really matter if the job I'm doing is causing me to be in pain and making things worse, then that isn't right, is it? Also, generally I'm much better at home, even if I'm doing strenuous things, and I don't think that FM necessarily should do that - so I definately put this down to work cause first and anything else second.

Anyways, please let us know if the Guaiphenasin actually does anything. (And, by the sound of it, good luck avoiding all the salicylates...)

Participant MNE1

Subject :

This message is in MIME format. Since your mail reader does not understand this format, some or all of this message may not be legible.

Hi X

Most of us have fairly bad posture and get tense at times in front of a computer.

It seems to be common knowledge among RSI specialists that neck and shoulder problems can cause pain elsewhere such as hands and wrists.

I would suggest you need to see a physio and try to stretch and relax your shoulders and neck. You could also try and get a touchpad to replace the mouse

Participant CJE26

Subject : Re: What if your doctor doesn't believe in RSI?

Sorry about your situation i am an employer so i can see both sides of coin i suffer badly if i had not been self employed (employer) i would have had at least one year off work if not terminal, however what can i do. I have bills to pay & so must suffer who am i being victimised by, my self or government?

## Appendix 4: List acceptable use policy

### LIST ACCEPTABLE USE POLICY

The purpose of the \_\_\_\_\_ is to provide a forum in which those who are affected by RSI can exchange information and offer one another support. Although anyone who has an interest in RSI is welcome to join, the list exists for the benefit of those with RSI, or those who are concerned about developing RSI. Subscribers with a commercial interest in RSI are asked to respect this primary purpose, and refrain from attempting to use this list to promote their own products or services.

To keep the information content of the group high, to avoid commercial bias, and to prevent unwanted postings, please note the following rules for acceptable use:

- Advertisements are not allowed on
2. In keeping with general practice on the net, signatures may contain brief (6 lines or less) information about products, URLs for websites, contact details, etc.
3. Anyone selling RSI-related products, who wants to announce e.g. a new product, or a change to an existing product, or a new website, etc., should write to listowner \_\_\_\_\_ rather than posting directly to the list.
4. \_\_\_\_\_ welcomes relevant contributions from subscribers who have commercial interests in RSI products, or offer RSI-related services. Most people with RSI problems want and need to know about products/services that might help them to cope/recover/return to work. However, such postings must be on-topic and objective, and must not cross the line between providing information and advertising.
5. In particular:

1. Discussion of a product should not be initiated, or prolonged beyond its natural lifespan, by anyone who sells that product.
2. When participating in list discussions about your product, please restrict the content of your posts to factual information about the product, e.g., "yes product x can be used with Windows", or, "yes product x comes with such and such a feature." Do not quote testimonials, and do not make claims about the efficacy of your product in reducing or curing or preventing RSI symptoms. References to independent research on the effectiveness of products will be welcome.
3. Do not ask list members to give you their postal addresses or other contact information.
4. The list should not be treated as a source from which to glean contact details for the purpose of selling services or products.

## Appendix 5: Ethical approval letter

Mohinder Watson  
Research Student  
Department of Physiotherapy  
Faculty of Health Studies  
Queen Margaret University College

Dr Catherine Roberts  
Registry Officer  
Queen Margaret University College  
Clerwood Terrace  
Edinburgh EH12 8TS

Tel: 0131 317 3219  
Email: croberts@qmuc.ac.uk

14 June 2002

Dear Mohinder Watson

**Request for Ethical Approval – A theoretical development of sufferers' experience of RSI and their perceptions of improvements for its management.**

Thank you for submitting the above protocol for ethical approval. The Research Ethics Sub-Committee considered your application at its meeting on 10 June, which your Director of Studies attended, and has granted ethical approval in principle.

The Sub-Committee commended your desire to engage in discussion about the ethical issues involved in this research and the fact that you have thought these through with your Director of Studies so carefully. Members felt it was sensible for you to apply for approval in stages.

The Sub-Committee however requires that you provide evidence of the Webmaster's consent for you to use the archive before full approval is granted by Convenor's Action. It is also recommended that you post a message on the site informing participants that you are carrying out this research and offering to share the findings with anyone who is interested.

A further condition of this approval is that you are required to notify the Sub-Committee, in advance, of any significant proposed deviation from the original protocol. Reports to the Sub-Committee are also required once the research is underway if there are any unexpected results or events which raise questions about the safety of the research. Notification of completion of the research is also required – the appropriate form (ETH4) is obtainable from me.

Please send your response to the Committee's requirement and recommendation directly to me.

Yours sincerely,

Catherine Roberts  
Secretary to the Research Ethics Sub-Committee

Cc Dr Denis Martin, Director of Studies

## Approval from ethics committee – follow up

**Mohinder Watson**

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**From:** Martin, Denis [DMartin@QMUC.ac.uk]  
**Sent:** lundi, 18. novembre 2002 12:56  
**To:** 'mohinderw@bluewin.ch'  
**Subject:** FW: Ethical considerations in your RSI research

-----Original Message-----

**From:** Hewlett, Nigel  
**Sent:** 15 November 2002 16:48  
**To:** Watson, Mohinder  
**Cc:** Roberts, Catherine; Martin, Denis  
**Subject:** Ethical considerations in your RSI research

Dear Mohinder

Catherine Roberts passed your messages to me for convenor's action. You got a helpful and interesting response from the list owner and I am happy to grant approval on behalf of the committee, for this aspect of your research.

Please keep us informed of any relevant developments. Meanwhile, I wish you the best of luck with your research.

Best wishes

Nigel

Nigel Hewlett  
Convenor of the Research Ethics Subcommittee  
Senior Lecturer and Laboratory Director  
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## Appendix 6: Ethical approval from list owner

Dear Mohinder,

I have your letter to [redacted] from 4th September, relating to using the [redacted] e-mail list archive for research purposes.

Additionally I had a conversation this morning with Denis Martin.

I am currently the "list owner" for this online community. This does not mean that I own the list in the legal sense, merely that I perform administrative functions for the list members, and occasionally guidance to members and others as to the acceptable use policy of the list. Practically this could mean that I exclude members who are behaving in an anti-social way. Unlike some lists there is no formal moderation of the conversations that occur, as I'm sure you know from your investigation so far.

I am certainly very glad that you are undertaking this research, and also pleased that the ethical dimensions of using the list archives in this way have been considered.

Given that the list itself is in the public domain, and that membership of it is freely available to anyone, I don't think there can be a principled objection to observers sitting in and doing whatever they like with their conclusions. What would be objectionable though is any unwanted direct contacts made to individual members as a result of such observations. Such contacts might be made for commercial reasons, for example.

Although I am favourably inclined to the research, I'm going to stall you for a while also I consult some other members of the community who may have a view .

I think that some sort of announcement of the community as to the direction of your research, and or assurances to of confidentiality etc would also go down very well. This would place you in good stead should you wish to invite (publicly of course) any members into focus groups for example.

I had also thought about some of the issues you might face in using the archives, and I discussed these as well with Denis.

Although the list is a safe haven for RSI sufferers, and is a much freer place than, say, a doctor's office, there are still going to be biases in what is said and who says it. You might find for example that there is a bias toward technically literate people who are inherently used to e-mail, or you may not, I don't know.

Is it safe to assume that what is reported on the list genuinely reflects the concerns of the members? You might ask who speaks and who doesn't (lurks). I think it will be useful information for you that there are around 300 registered members on the list. You may want to compare this with the number of people who actually contribute a regular basis.



Evidently the list has its own culture and tone. All e-mail lists do. This particular one, I have observed (you may draw your own conclusions from the archive) has a mature, stable culture. Does this mean that the deference of the lurkers is greater than for a newer more dynamic list?

I had an idea which might be useful to you. Rather than looking at all posts, the messages submitted by new members might be a better guide to what really concerns an RSI sufferer. New members will be unaffected by the influence of the group culture. They are usually in the midst of discovering their illness or the consequences of it. Therefore they have a particularly pressing need to share their emotions or make technical inquiries. You may see a release of fear and uncertainty at the same time as a relief at finding that the list exists.

The character of these initial post seems to me to be a much different from that of established members. Although not always. These posts are easy to find too, most of them have the subject "new member" !

I hope you find this helpful.

As I said I need to make some other inquiries and get some others on board before formally agreeing to this use of the list.

Another thing mentioned in the conversation with Denis is that I would be willing to look at the outcome of the research and comment on any conclusions you might have.

## **Second follow up confirmation of approval**

Mohinder,

Thanks for the added insight into the developement of your research.

Having discussed it a bit it is felt that there are no objections to you using the archives in the furtherance of your study. In other words, go ahead!



## Appendix 7: Topic schedule used in focus groups:

### Overall research question:

What is the experience of RSI from the individual's perspective?

Prior to the study participants were asked to write about their RSI experiences. The aim was to share this information within the group in order to stimulate discussion.

### Objective of focus groups:

To gain a deeper understanding of the experience of RSI through group discussions, by building on sensitising topics which appeared to be key areas of concern to sufferers during the archived e-mail analysis conducted in the first stage of the research.

### Key question was:

- What are sufferers' experiences of having RSI?

What do sufferers think, feel and do? What is it like for them?

### Underlying mini questions covered during focus groups were:

- What are sufferers' experiences of having and coping with RSI on a daily basis?
- What are sufferers' experiences of healthcare and healthcare professionals?  
Is a diagnosis important to sufferers and if so, why?
- How does RSI impact on sufferers' social role functioning, particularly in the workplace?

## Appendix 8: Consent form



Queen Margaret University College  
EDINBURGH

### Research Consent Form

**Title of study: The experience of having RSI and sufferers' perceptions of how RSI management could be improved.**

I have read and understood the Study Information Sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

Name of Participant: (please type your name ) \_\_\_\_\_

Signature of Investigator: (Mohinder Watson) \_\_\_\_\_

Date: \_\_\_\_\_

Further information is available from Mohinder Watson or Dr Denis Martin

Name of investigator: Mohinder Watson

Address: c/o Dr Denis Martin  
Scottish Network for Chronic Pain Research  
Queen Margaret University College,  
School of Health Sciences  
Duke Street, Leith,  
Edinburgh, EH6 8HF

Email: [mohinderw@bluewin.ch](mailto:mohinderw@bluewin.ch)

C:\My Documents\Consent Forms\RSIStudyConsent Form2.doc

## Appendix 9: Research publications



### TITLE: INTERNET BASED PAIN RESEARCH: AN ANALYSIS OF KEY CONCERNS OF INDIVIDUALS WITH REPETITIVE STRAIN INJURY (RSI) IDENTIFIED FROM EMAIL DISCUSSIONS



Mohinder Watson<sup>1</sup>, Denis Martin<sup>1</sup>, Lindsey Carroll<sup>2</sup> & Derek Jones<sup>1</sup>

1. School of Health Sciences, Queen Margaret University College, Edinburgh, Scotland, UK. 2. Dept. Psychology, Glasgow Caledonian University, Glasgow, UK.

#### Background

RSI represents a significant problem contributing to ill health in the workplace within EU member Countries (Buckle & Devereaux, 1999). This view is endorsed by the European Trade Union Technical Bureau (TUTB) and the European Trade Union Confederation (ETUC).

In the UK the Health & Safety Executive, estimating that RSI costs around £1.25 billion per year, have given the issue a high priority on their strategic plan for 2001-2004.

Controversy still remains over its legitimacy as a medical condition, diagnosis, aetiology, work relatedness and management. (Reid et al 1991, Tyrer, 1999).



"RSI does not exist." Judge Prosser, in *Mughal v Reuters*.

"The claimant does suffer from a work related upper limb disorder or injury albeit there are no physical signs of it." Judge Tyzack, in *Gallagher v Bond Pearce*.

(An award of £87,000 was made.)

This study is part of an in-depth investigation of sufferers' experience of living with RSI and their recommendations for improvements in the management of RSI.

#### Aim

The aim of the study was to identify key concerns of individuals with RSI to formulate an interview topic schedule for use in electronic focus groups.

#### Method

**Participants:** Participants were participants in an email RSI discussion group. Excluded were those who were not suffering from RSI (such as sales representatives).

**Procedure:** The archives from the discussion list covering an arbitrarily chosen six month period were downloaded. Every 2<sup>nd</sup> email (n=590 was selected). 56 emails were excluded.

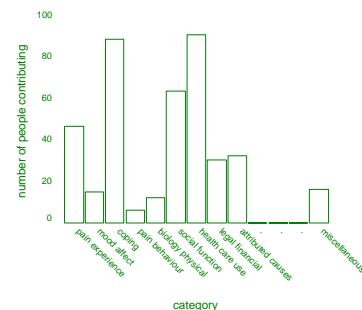
**Analysis:** The remaining 534 emails were analysed thematically starting with a framework based on 7 domains of chronic pain described by Morley et al (1999): pain experience, use of health-care systems; mood; coping; social-role functioning; biological/functional changes and pain behaviour. The initial framework evolved with the addition of new categories and reinterpretation of original categories. The analysis was facilitated by NVIVO™.

#### ACKNOWLEDGEMENTS

Members of the support group and listowner.

#### Results

The figure below shows the number of people contributing comments within the categories.



All of the categories in the initial framework were addressed by the participants. Separate categories were created for legal/financial issues and attributed causes.

#### Conclusions

The key issues related to the use of health-care systems, social-role functioning (in particular work), pain experience and coping (information exchange and support).

Noticeably absent was much discussion about close interpersonal relationships.

The discussion of pain experience was high amongst newcomers introducing themselves to the group but this was markedly less so in more established members.

The legal/financial issues included private healthcare costs, real and potential loss of earnings, litigation and claiming disability living allowance.

Analysis is continuing to refine the categorisation.

#### REFERENCES

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- Tyrer, S P (1999) *Repetitive Strain Injury Pain Reviews*: 6: 155-166

**Contact:** Mohinder Watson, [mohinderw@bluewin.ch](mailto:mohinderw@bluewin.ch), Avenue de Crousaz 2c, Lausanne 1010, Switzerland



